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Establishing a protocol for building a national database for Fetal Alcohol Spectrum Disorder diagnostic assessment-related information in Canada

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ABSTRACT

Introduction: Fetal Alcohol Spectrum Disorder (FASD) is one of the most common neurodevelopmental disorders in North America. It is a complex disability, associated with challenges in cognitive, behavioural, and social-emotional functioning, as well as an increased risk of physical and mental health comorbidities, and difficulties in daily living across the lifespan. Previous attempts to characterize the profile of this population have been hampered by differences in data collected across studies, regional discrepancies in terminology and definitions, and a lack of tools to integrate comprehensive datasets.

Methods and analysis: The goals of this study are to use the Canadian National FASD Database, a national repository of FASD assessment-related information, to better understand the functional profile, comorbidities, intervention needs, and difficulties in daily living experienced by individuals assessed for FASD across the lifespan. We will also examine what factors may be the most sensitive predictors of receiving an FASD diagnosis. Data will be analyzed from over 2,500 records collected between 2010 and 2020 (ongoing) from 29 FASD diagnostic clinics in seven provinces and territories. Data collection is ongoing, and analysis will be performed on a bi-annual basis to continue to hone our understanding of the needs, strengths, and outcomes of individuals assessed for FASD in Canada. This research is critical for refining FASD assessment and diagnostic practice, enabling accurate and early identification of individuals with FASD, and connecting individuals with FASD and their families to comprehensive and effective services and resources to support healthy developmental trajectories. **Ethics and dissemination:** Ethics approval for the National FASD Database Project was obtained from the Ottawa Health Science Network Research Ethics Board. As new knowledge is gained from this project, findings will be disseminated through publications, presentations, and feedback to participating clinics, with the ultimate goal of informing FASD research, practice, and policy.

Key words: Fetal Alcohol Spectrum Disorder; prenatal alcohol exposure; assessment and diagnosis; national database; developmental trajectories

Strengths and limitations of this study

1. The Canadian National FASD Database is the first and only existing standardized patient-level

    database of individuals assessed for FASD in Canada, which allows for the identification of trends

    related to the prevalence and diagnosis of FASD and associated features.

2. Ongoing data collection enables the monitoring of changes in population-level profiles, needs, and

    outcomes of individuals assessed for FASD in Canada, as well as access to timely information to

    guide FASD research, practice, and policy.

3. The Database was developed in consultation with governments, clinicians, researchers, and

    individuals with FASD and their families, ensuring that information collected is relevant and

    meaningful for individuals with FASD and those who support them.

4. Data is collected from most, but not all, clinics in Canada, and there are several provincial and

    territorial jurisdictions that are not represented in the Database.

5. Information collected is cross-sectional, limiting our ability to explore longitudinal trends or follow

    the developmental trajectories of individuals with FASD across the lifespan.

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INTRODUCTION

Health and human development

Health vulnerability and associated developmental trajectories are rooted in the prenatal stage

and first years of life, both of which are critical periods involving complex interactions between

biological, genetic, and environmental conditions. Many determinants of health contribute to optimal

development and are relevant for all human beings, regardless of culture or background. Maternal and

fetal health, the early caregiving environment and family influences, poverty and malnutrition,

neighbourhood factors, and the broader socio-political context can all have profound impacts on human

development and healthy outcomes.[1] In the long term, poor physical, mental, and socioemotional

development in childhood is linked to unfavourable outcomes such as school failure, delinquency,

unemployment, and poor health in adulthood.[2]

Researchers have worked hard to identify permissive and protective factors that optimize

developmental outcomes, from preconception through to adulthood. The presence of a diagnosable

medical condition early in life can greatly impact an individual's health trajectory throughout the

lifespan.[3] Data strongly show that providing early interventions and supports can have protective

effects, mitigate difficulties in daily living, and provide a foundation for healthier trajectories.[4]

However, in order to achieve these benefits, it is essential that individuals who are at risk are accurately

identified and connected with appropriate and effective supports.

Developmental trajectories and prenatal alcohol exposure

Prenatal alcohol exposure (PAE) is associated with a broad range of neurodevelopmental and

behavioural needs which, without standardized mechanisms for identification, can be missed. When

needs are not recognized, individuals with PAE can experience substantial challenges, and critical

opportunities for early interventions to improve outcomes for individuals and families may be missed.[5]

Indeed, researchers have shown that early identification is one of the most powerful factors to mitigate the lifelong adverse effects of PAE.[4, 6]

Because of the complex and heterogeneous consequences of PAE, a standardized data collection protocol using common data fields can be a powerful and comprehensive tool for understanding PAE and its associated impacts. At a national level, such a protocol allows for the large-scale examination of the neurodevelopmental effects of PAE, as well as the identification of other social and environmental factors that may influence outcomes for individuals with PAE. Moreover, it can improve our understanding of the supports, strategies, and interventions that may reduce challenges and optimize strengths and abilities for individuals with PAE and their families.

Fetal Alcohol Spectrum Disorder

When the brain- and body-based impacts of PAE reach a clinical threshold, individuals may be diagnosed with Fetal Alcohol Spectrum Disorder (FASD).[7] FASD is a lifelong disability associated with difficulties in motor function, learning, memory, attention, communication, emotional regulation, and social skills. Individuals with FASD require ongoing support with daily living and are at high risk for compromised developmental trajectories, stemming from the neurodevelopmental impacts of PAE, compounded by complex biopsychosocial factors. Individuals with FASD often have extensive patterns of impairment with co-occurring physical and mental health conditions that influence their clinical presentation, treatment recommendations, and potential outcomes.[5, 8-10] They also often experience early[11] and ongoing environmental adversity[5, 6, 12] and disruption in the caregiving environment [13, 14] which can impact social, behavioural, and emotional development. [13, 15, 16] Difficulties with daily living are common among individuals with FASD, including problems with school and employment; independence and housing; mental health disorders and substance misuse; and interaction with the justice system.[5, 6]

FASD affects approximately 4% of the Canadian population and is a complex social and public

health issue.[17, 18] As with other developmental disabilities, early diagnosis of FASD and access to

evidence-based interventions are crucial for improving long-term outcomes.[6] Individuals with FASD

are an exceptionally complex and heterogeneous group, and there is a strong interest among

researchers and clinicians in characterizing the profiles of these individuals.[19, 20] However, there are

several challenges with characterizing this population, such as inconsistent definitions of the disability,

varying diagnostic systems and approaches, as well as the resource-intensive multidisciplinary diagnostic

process itself. Attempts to compare data across FASD studies have largely failed because of the

discrepancies in these definitions and approaches. These challenges highlight the potential utility of a

consistent, nation-wide database to inform FASD research, practice, and policy.

Measuring FASD at the population level in Canada

In Canada, there has been a paucity of population-level information about individuals with PAE

and FASD, which is critical for building meaningful, cost-effective, and appropriately distributed

programming and interventions. Over the past decade, Canadian researchers have sought to address

this gap by working together to develop and contribute to a standardized database with a common set

of indicators. The Universal FASDataForm Project was initiated in 2010 in collaboration with Canadian

FASD diagnostic clinics to determine if standardized collection of assessment-related data was a

possibility, and then subsequently to generate the first clinical dataset for FASD, and identify trends and

modalities related to prevention, prevalence, and diagnosis of FASD.[21] The FASDataForm was revised

in 2015 to refine the process of collecting and comparing common data indicators, resulting in the

updated (and renamed) National FASD Database Project. The main purpose of the Database Project is to

capture information related to the assessment and diagnosis of FASD in Canada, including information

on the physical and mental health needs, and the functional difficulties and difficulties in daily living

experienced by individuals presenting for FASD assessment across the country.

In the current study, our goal is to investigate the profile and experiences of individuals assessed for FASD in Canada. Analysis of data from the Database will allow us to interpret and disseminate findings on characteristics, associated features, and outcomes of individuals presenting for an FASD assessment. The study is guided by the following research questions:

1. *What is the functional profile of individuals assessed for FASD? How is it different than those without FASD in the general population?*

2. *What are the physical and mental health comorbidities associated with FASD? How do these rates compare to the non-FASD general population?*

3. *What are the most sensitive predictive factors for an FASD diagnosis?*

   a. *Which non-diagnostic factors are the most strongly predictive of FASD?*

   b. *Which diagnostic and individual factors are the most strongly predictive of FASD?*

4. *What are the most common recommendations for interventions for individuals assessed for FASD?*

5. *What factors may contribute to or protect against the difficulties in daily living associated with FASD?*

METHODS AND ANALYSIS

Data source and variables

The National FASD Database is an ongoing data repository comprised of clinical and diagnostic findings for individuals of all ages presenting for an FASD assessment to participating clinics (n = 29) from seven provinces and territories in Canada. The Database contains responses from a 287-item bilingual (English or French) questionnaire, completed online through the RedCap platform, usually by the clinic intake co-ordinator. Data fields are populated based on chart review of each individual who has completed the FASD assessment process. The Database includes records generated over two data collection periods between 2010 and 2020, with ongoing entry.

The Database captures a wide range of information including individual demographics, referral

source and reasons for referral, use of screening measures, living situation, family history of FASD,

prenatal exposure to alcohol and other teratogens, and early life adversity. Aligning with the current

Canadian Diagnostic Guideline criteria,[7] data is recorded for each individual on confirmation of PAE

above risk levels[i], measurement of sentinel facial features (SFF)[ii], assessment of neurodevelopmental

functioning in 10 domains[iii], and FASD diagnostic outcome. Associated features of FASD are also

recorded, as well as comprehensive information about the client's physical and mental health, including

comorbidities, medication, substance use, and difficulties in daily living. Finally, data is collected on

recommendations for intervention, and whether these recommended services are available near the

client's home (see Appendix 1 for full questionnaire, and Table 1 for data collected for this study).

Table 1. Data collected.

Demographics	Age; gender; living situation; region
Historical data	Prenatal exposure to other substances; family history of FASD; trauma; attachment issues; physical or sexual abuse
Diagnostic criteria	Confirmation of PAE; facial measurements; neurodevelopmental functioning
Diagnostic outcome	FASD with SFF; FASD without SFF; At Risk for Neurodevelopmental Disorder (NDD)/FASD; No FASD
Associated features	Sleep problems; sensory sensitivities; sensory processing issues; slow processing speed; gender identity issues
Physical health comorbidities	Congenital malformations; auditory deficit; visual deficit; growth restriction; failure to thrive; microcephaly; neurological conditions; head and neck issues; cleft lip/palate; cardiovascular conditions; respiratory problems; endocrinological condition; musculoskeletal condition; infectious disease
Mental health comorbidities	Intellectual Disability; Attention Deficit Hyperactivity Disorder; Attachment Disorder; Developmental Coordination Disorder; Language Disorder/impairment; Tourette Syndrome; Anxiety Disorder; Mood Disorder; Autism Spectrum Disorder; Bipolar Disorder; Conduct Disorder; Oppositional Defiant Disorder; Obsessive Compulsive Disorder; Post-Traumatic Stress Disorder; Schizophrenia; Substance Use Disorder; Suicidality

[i] Under the Canadian Diagnostic Guideline, above-risk PAE threshold is defined as ≥7 standard drinks per week, or ≥2 episodes of drinking of ≥4 drinks on the same occasion. FASD with SFF may be diagnosed in the absence of confirmed above-risk PAE given the specificity of simultaneous presentation of three SFFs to PAE.
[ii] Palpebral fissure length ≥2 standard deviations below the mean (<3rd percentile), philtrum rated 4 or 5 on a 5-point scale of the University of Washington (UW) Lip-Philtrum Guide, upper lip rated 4 or 5 on a 5-point scale of the UW Guide.[1]
[iii] The 10 neurodevelopmental domains, as outlined in the Canadian Diagnostic Guideline, include: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication.

Recommendations	Coaching or support; FASD-specific (education or intervention); counselling (support group, individual therapy, or couples/family); respite or daycare; substance use treatment; sexual health education; anger management; spousal abuse intervention; mental health support; basic needs (income support, food bank, safety precautions); guardianship, power of attorney, personal directive, or other substitute decision making; child protection; legal services (legal aid, services for civil or family court issues); allied health services (speech and language pathologist, occupational therapy, behaviour therapy); medication/psychopharmacology or medical referral; accommodations/adaptation in environment, expectations, supports, or routine; anticipatory guidance/prevention; reassessment
Difficulties in daily living	School problems (requiring teacher assistants, expulsion/suspension); employment problems; problems with living independently; housing problems (requiring assisted or sheltered housing); legal problems (victimization, offending, custody/family court issues, incarceration)

As of summer, 2020, the Database contained more than 2,500 records collected between 2010 and

2020. All individuals were evaluated by a multi-disciplinary team according to the Canadian Diagnostic

Guidelines for FASD.[7] Of the 2,019 individual records that included a diagnostic outcome, 60%

received an FASD diagnosis (51% without SFF and 9% with SFF), and 11% were designated At-Risk of

NDD/FASD. The mean age of individuals was 14 years old (range 0 to 60 years), and 59% of the sample

identified as male.

Patient and Public Involvement

Patients, clinicians and families have expressed the desire to be able to learn about FASD and its

presentation with respect to brain impairment and physical and mental health co-morbidities, with the

goal of better understanding leading to more targeted and effective supports and services. Individuals

with FASD have expressed the desire to learn if their experiences are similar to the experiences of others

with the same diagnosis, so they can contribute to the research field.

Data fields and their indicators were developed by a rigorous process where diagnosticians and

family members of those with FASD (the public) , adults with FASD (patients) across Canada and

internationally provided input to ensure that data collection would be feasible and analysis would

provide meaningful information and results. For example, adults with FASD reported that they wanted

to obtain more information on the trajectory of physican and mental health co-morbidities across the ages, and their specific requests were included as indicators. In this way, families (the public) and individuals with FASD (patients) participated in developing the datafields the comprise the Database, and helped to define the scope of the dataset, especially related to recommendations. Participating clinics and families who opted in to participate in the research helped to define the project's research questions and will continue to do so on an annual basis. Regular communication with clinics including conference calls, annual face-to-face meetings, quarterly newsletters, and individual clinic updates allows for ongoing collaboration and refinement of the data collection process. Feedback and data are provided on a bi-annual basis to each participating clinic for their own use and comparison with provincial and national aggregate datasets. Results will also be shared in a format that clinics can share with their patients and families, and presented at national and international meetings that are attended by individuals with FASD.

Data analysis plan

Statistical analyses will be performed bi-annually on datasets extracted in the fall (September 30) and spring (April 30) of each year, using SPSS Statistics 27 software. All data will be grouped categorically. For demographic information, data will be coded as follows: age cohort (0-5 years, 6-12 years, 13-17 years, 18+ years), gender (male, female, other), living situation (independent, with biological mother, biological father, with other family member[s], foster care [non-family], adoptive parent[s], group home, homeless, in custody, other), and region (Northern and Western Canada, the Prairies, Central Canada, Atlantic Canada). For diagnostic criteria, confirmation of PAE will be coded as present, absent, or unconfirmed/unknown; facial measurements will be coded as the number of SFF present (0, 1, 2, 3, or inconclusive); neurodevelopmental functioning in each domain will be coded dichotomously (significantly impaired vs. not significantly impaired); and diagnosis will be coded as one of the four outcomes. All other data will be coded dichotomously as either absent or present.

Descriptive statistics will be used to characterize the sample for categorical data. We will

conduct Pearson chi-square tests and logistic regression to compare patterns between groups, examine

predictive factors, and explore strengths of association. Where available, prevalence data (e.g.,

comorbidities) will be compared to rates found in neurotypical populations.

Research question 1

What is the functional profile of individuals assessed for FASD and how is it different than those without

FASD in the general population?

The functional profile of individuals assessed for FASD will be described in terms of the

frequencies and patterns of neurodevelopmental impairment, and associated difficulties. Profiles will be

compared between diagnostic outcomes, age cohorts, and genders. We will also examine the patterns

of each diagnostic criterion within diagnostic outcomes, age cohorts, and genders. Findings in this area

will provide valuable information about the needs and strengths of individuals with FASD, and improve

our understanding of where interventions may be targeted to improve outcomes for individuals with

FASD.

Research question 2

What are the physical and mental health comorbidities associated with FASD? How do these rates

compare to the non-FASD general population?

The frequencies and patterns of health comorbidities among individuals assessed for FASD will

be examined, and compared across diagnostic outcomes, age cohorts, and genders. The strengths of

association will be examined between physical and mental health comorbidities and diagnostic

outcomes, pattern of brain impairment, and difficulties in daily living. This information will allow for a

more holistic and comprehensive understanding of the needs of individuals with FASD across the

lifespan, and uncover areas of difficulty that may warrant additional services and supports.

Research question 3

A. Which non-diagnostic factors are the most strongly predictive of FASD?

With this question, we aim to identify the combinations of demographic, historical, physical and

mental health, and adversity factors that are most strongly associated with being diagnosed with FASD

for different age cohorts and genders. We will also explore the strengths of association between

predictive factors and FASD diagnosis (any FASD diagnosis and specific FASD diagnostic categories).

Predictive models will be developed to determine sensitivity and specificity of combinations of factors

associated with being diagnosed with FASD. It is anticipated that findings from these analyses will

further refine FASD diagnostic criteria, and lead to more sensitive screening tools across the life span.

B. Which diagnostic and individual factors are the most strongly predictive of FASD?

Diagnostic criteria data will be analysed collectively, independently, and interdependently to

explore which criteria may always co-occur, which are exclusive and predictive of FASD, and how non-

diagnostic factors including age, gender, history, or comorbidities may influence whether an individual

receives an FASD diagnosis.

Research question 4

What are the most common recommendations for interventions for individuals assessed for FASD?

The frequency and pattern of recommendations made for each diagnostic outcome, age cohort,

gender, and region will be examined. We will also explore whether and how different types of

recommendations are associated with specific areas of brain impairment and other physical and mental

health comorbidities. Recommendations will be compared across regions to develop intervention maps

for understanding what services are needed, and where they may be lacking. This information will allow

us to better understand practical areas where individuals with PAE require support across their lifespan,

and what factors influence the recommendations made. This information will be useful for clinicians to

influence policy and practice and advocate for consistency in service availability across the country.

Research question 5

What factors may contribute to or protect against the difficulties in daily living associated with FASD?

To explore this question, we will characterize and compare difficulties in daily living across diagnostic outcomes, age cohorts, and genders. We will also examine the strengths of association between difficulties in daily living and demographic and historical factors, diagnostic criteria, comorbidities, and associated features. Although data in the Database is cross-sectional, this examination will allow us to identify factors that may be related to difficulties in daily living across the life span, and circumstances within which to introduce and optimize supports.

ETHICS AND DISSEMINATION

Ethics approval for this project was obtained from the Ottawa Health Science Network Research Ethics Board (protocol # 20160423-0H1), and is renewed on an annual basis. The Database is hosted on the secure RedCap platform at the University of Alberta, in Edmonton, Alberta, Canada. RedCap is an important tool for data access, linkages, and mobilization. Upon agreeing to participate in the project, clinics receive a random identification code, and the principal investigator and statistics team is blind to the coding.

Researchers who wish to use the data for their own work are required to obtain approval from their own institutional ethics boards, and apply to a Database oversight committee. Applications must align with the intent and ethics of the overall project. On approval, an anonymised, aggregated dataset is downloaded from the server and sent to the researchers via a secure, password-protected link. This external use of data stimulates the development of new research questions and collaborations, and expands the potential impact of the Database.

Several studies have been published from the Database[5, 21, 22] and many more are underway. As new knowledge is gained, findings will be disseminated through presentations at local, national, or international meetings; publications in academic and grey literature; and regular feedback to participating clinics, all with the goal of informing FASD research, practice, and policy.

DISCUSSION

The National FASD Database provides rich information, both medical and behavioural, about individuals assessed for FASD in Canada across the lifespan. This information contributes evidence related to diagnostic criteria, determining the need for and availability of intervention supports, and stimulating further research. Information collected in the Database will improve our understanding of the challenges, strengths, clinical profiles, functional needs and strengths, and outcomes of Canadians who are exposed to alcohol prenatally. We know that Canadians presenting at FASD clinics experience substantial difficulties navigating daily life,[5] and continued data collection and analysis through the Database has important implications for guiding practice and policy responses to improve quality of life for these individuals and their families. The Database also captures important information about individuals who are assessed for FASD but are not diagnosed. Although evidence in this area is limited, researchers suggest that clinically-referred individuals with PAE who do not meet the criteria for a formal diagnosis may nonetheless experience complex needs requiring timely care.[5, 23] Information on the functional needs and complex presentations of all Canadians with PAE allows for a comprehensive understanding of areas where supports are needed, and guides efforts to provide the most appropriate services and interventions.

Collecting information from Canadians with PAE across the lifespan allows us to understand more about the trajectory of FASD in Canada, whether the common experiences of Canadians with FASD change systematically over time, and how services and policies should be modified to meet these changing needs. The Database also allows us to compare the profiles and characteristics of Canadians with FASD to other subgroups of the population to identify unique or pressing needs. Examining trends in FASD data at a regional level will allow us to determine whether the needs of individuals with FASD differ in specific locations, and whether tailored approaches to service delivery are needed and available in different parts of the country. Similarly, findings from the Database Project will reveal important

information about the gaps between FASD diagnosis and service availability for families impacted by

FASD. Individuals with FASD and their caregivers require access to coordinated supports and services

that are informed by the pattern of brain impairment from the diagnostic assessment.[24] In the current

service system, these supports may be lacking, and findings from the Database will highlight the most

common recommendations, as well as the most significant gaps in FASD service provision.

Finally, the Database provides a structure for active communication and collaboration among all

clinics in Canada that provide FASD diagnostic services. Already, there is preliminary data to suggest that

FASD clinicians are operating with a good deal of consistency across the country,[25, 26] which may in

part be attributable to engagement with the National Database. This coordinated approach allows for a

consistent application of FASD best practices, a cohesive community of practice, and a stronger network

of experts working together to support improved outcomes for individuals with FASD and their families.

Limitations and challenges

The Database Project has several limitations. First, despite our goal to have every diagnostic

clinic in Canada (approximately 60 to date) contributing to the Database, some jurisdictions are not

represented. We have made significant efforts to recruit clinics from every Canadian province and

territory, and to reduce barriers to participation, we continue to assist clinics with their local ethics

applications. Nonetheless, there are regional gaps in the data that limit nation-wide conclusions.

Second, because the information in the Database is cross-sectional, it is not possible to examine

longitudinal trends or to follow-up with individuals to see how their profiles, needs, and strengths

change throughout their lifespan. However, because data is collected from individuals at various life

stages, general snapshot observations can be made about different experiences or challenges that may

be most relevant for individuals with FASD as they age. Relatedly, this project will be able to identify

important focal points that warrant follow-up using longitudinal approaches to best understand this

population. Lastly, since the Database is a clinical dataset rather than a true research database, there is

no control group of neurotypical individuals, or of individuals who have PAE but do not experience

problems significant enough to trigger a referral for assessment. Therefore, in order to contextualize

findings from the Database, we typically must compare results with existing literature from neurotypical

populations (e.g., prevalence of mental health disorders).

The legal, ethical, and administrative processing that is necessary to conduct research of this

scope across jurisdictional lines is possible, but arduous, and may limit the level of detail included in the

Database. A great deal of consideration was given to the development of each question, balancing the

need to derive meaningful information with the priority that data entry must not be burdensome for

clinics. However, through clinic consultation, we have learned that additional valuable information

would be available for collection in future iterations of the Database. For instance, although in-depth

information regarding the amount and timing of PAE was thought to be unattainable at the time of the

Database development, we have learned that most clinics have access to this information and that it

would be feasible to collect in the future.

Finally, although the Database is structured according to the Canadian FASD Diagnostic

Guideline,[7] and guidance is provided to clinics for measuring and reporting on the diagnostic criteria,

information in the Dataset still comes from numerous sources. These include self-report, record review,

or screening tools, and this variability may result in inconsistent reporting. In order to mitigate this,

participating clinics have been provided with a list of recommended assessment tools for each of the

measurements, where appropriate. Clinics also use a collaborative online platform to share ideas and

experiences related to data field interpretation and data entry, in order to increase consistency in the

use of the Database. Without funding for each clinic, it is necessary to rely on the enthusiasm and

investment of clinicians to sustain the partnership. Without the efforts of the participating clinics and

the individuals and families who consent to their data collection, the Database would not be possible.

CONCLUSION

Canada's National FASD Database provides an important framework for characterizing and exploring the needs and outcomes of individuals with PAE across the life span. The comprehensive and nation-wide scope of the Database enables researchers to examine questions that have not previously been possible to explore. The Database provides a unique and timely opportunity to monitor the prevalence of FASD and associated health comorbidities at a population level, as well as evidence to determine optimal interventions mapped to physical, mental, and neurodevelopmental issues and optimize developmental trajectories of individuals prenatally exposed to alcohol. The clinical presentation of Canadians with PAE and FASD is highly complex, and information derived from the Database provides direct evidence of areas where supports are needed. Critically, this information can guide our efforts to provide the most appropriate services and interventions to support positive outcomes for individuals with FASD, their caregivers, families, and communities.

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AUTHORS' CONTRIBUTIONS

J Cook lead the conceptualization of the design of this project, the applications for funding and the overall development of the database. K Unsworth lead the recruitment of participants and clinics, development of the knowledge translation plan and the reporting of the work. K Flannigan refined research questions, piloted the survey tool and provided interpretation of the data. All authors drafted sections of the manuscript and revised it critically. All approve this final version for publication and agree to be accountable for all aspects of the work.

COMPETING INTERESTS STATEMENT

None to declare.

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CanFASD Dataform

Preferred language/Langue de préférence: ◯ English   ◯ Français

DEMOGRAPHIC INFORMATION AND PATIENT CHARACTERISTICS

Identification

Site ID

_____

Country

◯ Canada
◯ Australia
◯ New Zealand
◯ United States
◯ United Kingdom
◯ France
◯ Other

Please specify

_____

Province/Territory

◯ AB
◯ BC
◯ MB
◯ NB
◯ NS
◯ NL
◯ NWT
◯ NU
◯ ON
◯ QC
◯ SK
◯ YK

Type of assessment

◯ Initial Assessment
◯ Re-assessment
◯ Follow-up

If being re-assessed, was the individual previously given an "At Risk" designation?

◯ Yes
◯ No
◯ Unknown

Date of Referral

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

Year

_____

Source of Referral

○ Social Services Agency (e.g., Child and Family Services agency, community support agency)
○ Medical Referral
○ Education System (e.g., school, daycare)
○ Legal System
○ Self
○ Family referral (e.g., biological, foster, adoptive parent)
○ Other

Specify

_____

Reason(s) for referral

Please check all that apply

☐ Behavioural issues
☐ Learning difficulties
☐ Difficulties with the law
☐ Developmental delays/delays to meet developmental milestones
☐ Adaptive living problems
☐ Confirmed prenatal alcohol exposure
☐ Social skills difficulties
☐ Self-regulation difficulties (feeding, sleeping, sensory)
☐ Reassessment
☐ Follow-up
☐ Establish eligibility for supports (e.g., financial or developmental support programs)
☐ Other

Please specify

_____

Was a screening tool used for referral?   ○ No   ○ Yes

Which tool?

_____

Who did the screen?

_____

Date of Diagnostic Assessment

REDCap

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

| Year | _____ |

| Sex | ○ Male ○ Female |

| Gender identity | ○ Male ○ Female ○ Other |

| Please specify | _____ |

Date of Birth

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

| Year | _____ |

Which ethnic group(s) does this person most identify with?

- ☐ Caucasian
- ☐ Indigenous
- ☐ African American
- ☐ Latin American
- ☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
- ☐ West Asian (e.g. Iranian, Afghan, etc.)
- ☐ Chinese
- ☐ Filipino
- ☐ Korean
- ☐ Japanese
- ☐ Southeast Asian (e.g. Vietnamese, Cambodia, Laotian, Thai, etc.)
- ☐ Arab
- ☐ Other
- ☐ Unknown

Specify

_____

Current living situation

- ◯ Independent
- ◯ With biological mother
- ◯ With biological father
- ◯ With other family member(s)
- ◯ Foster care (non-family member)
- ◯ Adoptive parent(s)
- ◯ Group home
- ◯ Homeless
- ◯ In custody
- ◯ Other

Specify other family member(s)

_____

Specify

_____

Has a biological parent been diagnosed with FASD?   ◯ No   ◯ Yes   ◯ Unknown

Has a sibling been diagnosed with FASD?

- ◯ No
- ◯ Yes
- ◯ Unknown
- ◯ Not applicable (no siblings)

ASSESSMENT OF PRENATAL ALCOHOL EXPOSURE

Prenatal alcohol exposure is:

- ◯ Absent (Confirmed)
- ◯ Present (Confirmed)
- ◯ Unconfirmed
- ◯ Unknown

Please specify source, if known

_____

Other prenatal exposures:

	Absent (Confirmed)	Present (Confirmed)	Unknown
Nicotine	○	○	○
Opiates	○	○	○
Marijuana/cannabis	○	○	○
Cocaine/crack	○	○	○
Methamphetamine/speed	○	○	○
Prescription medications	○	○	○
Other Exposures	○	○	○

Please specify

_____

Other factors

Please check all that apply

☐ Post-natal trauma
☐ Attachment issues
☐ Sexual or physical abuse
☐ Other

Please specify

_____

SENTINEL FACIAL FEATURES

Palpebral fissure norms used:

☐ Canadian norms
☐ Thomas
☐ Scandinavian
☐ Other

Please specify

_____

Palpebral fissure length

○ >-1 SD
○ > -2 SD & < -1 SD
○ < -2 SD

Philtrum smoothness

Score on lip-philtrum guide

○ 1
○ 2
○ 3
○ 4
○ 5

Upper lip thinness

Score on lip-philtrum guide

○ 1
○ 2
○ 3
○ 4
○ 5

Total number of sentinel facial features present

○ 0
○ 1
○ 2
○ 3
○ Inconclusive

NEUROBEHAVIOURAL ASSESSMENT

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Brain Domain Assessment Results

Please indicate how the following brain domain was assessed

	Not impaired	Significant Impairment	Not Assessed	Incomplete
Motor skills	○	○	○	○
Neuroanatomy/Neurophysiology	○	○	○	○
Cognition	○	○	○	○
Language	○	○	○	○
Academic achievement	○	○	○	○
Memory	○	○	○	○
Attention	○	○	○	○
Executive function including impulse control	○	○	○	○
Affect Regulation	○	○	○	○
Adaptive behaviour, social skills, or social communication	○	○	○	○

Full scale IQ	○ Less than 70
	○ 70
	○ 71-85
	○ greater than 85
	○ Unable to calculate

Diagnosis	○ FASD with sentinel facial features
	○ FASD without sentinel facial features
	○ At risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure
	○ No FASD Diagnosis

Do you use another diagnostic schema to record information (i.e. 4-digit code)?	○ No ○ Yes

Please provide the 4-digit diagnostic code

_____

Other associated features	☐ Sleep problems
	☐ Sensory sensitives
Please check all that apply	☐ Sensory processing
	☐ Trauma
	☐ Slower processing speed
	☐ Gender identity
	☐ Other

Please specify

_____

Other diagnoses

Note: Assessment did not have to occur at this clinic.

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	No (Assessed but not diagnosed)	Yes (Assessed and diagnosed)	Not assessed
Congenital malformations	○	○	○
Intellectual disability	○	○	○
ADD/ADHD	○	○	○
Attachment disorder	○	○	○
Developmental coordination disorder	○	○	○
Language disorder/impairment	○	○	○
Auditory deficit	○	○	○
Visual deficit	○	○	○
Tourette's	○	○	○
Anxiety disorder	○	○	○
Autism Spectrum Disorders	○	○	○
Bipolar disorder	○	○	○
Conduct disorder	○	○	○
Mood disorder	○	○	○
Obsessive compulsive disorder	○	○	○
Personality disorder	○	○	○
PTSD	○	○	○
Schizophrenia	○	○	○
Substance abuse disorder	○	○	○
Suicide attempt(s)/Ideation	○	○	○
Oppositional defiant disorder	○	○	○
Other	○	○	○

Please specify

_____

MEDICAL HEALTH HISTORY

Growth restriction   ○ No   ○ Yes

Please specify height and weight percentiles

_____

Microcephaly   ○ Yes   ○ No

Failure to thrive   ○ yes   ○ No

Neurological conditions   ○ No   ○ Yes

Please specify

_____

Mental health   ○ No   ○ Yes

BMJ Open

Please specify

_____

Head and neck issues   ○ No   ○ Yes

Please specify

_____

Cleft Lip Palate   ○ Yes   ○ No

Cardiovascular conditions   ○ No   ○ Yes

Please specify

_____

Respiratory system   ○ No   ○ Yes

Please specify

_____

Endocrinological conditions   ○ No   ○ Yes

Please specify

_____

Musculoskeletal   ○ No   ○ Yes

Please specify

_____

Infectious diseases   ○ No   ○ Yes

Please specify

_____

Other   ○ No   ○ Yes

Please specify

_____

MEDICATION

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	No	Yes
Omega-3	○	○
Choline	○	○
Glutamine	○	○
Aripiprazole	○	○
Vortioxetine	○	○
Minocycline	○	○
Bupropion	○	○
Buspirone	○	○
Clozapine	○	○
Melatonin	○	○

Please list all other current medications

Stimulants

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

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Medication 5:

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Medication 6:

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Medication 7:

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Medication 8:

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Medication 9:

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Medication 10:

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Anti-depressants

Medication 1:

_____

BMJ Open

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2   Medication 2:
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                                                    _____
4
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7   _____
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10   _____
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13   _____
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16   _____
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18   Medication 7:
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20   _____
21   Medication 8:
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23   _____
24   Medication 9:
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26   _____
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28   Medication 10:
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30   _____
31   Anti-psychotics
32
33
34   Medication 1:
35   _____
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37   Medication 2:
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39   _____
40   Medication 3:
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42   _____
43   Medication 4:
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45   _____
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47   Medication 5:
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49   _____
50   Medication 6:
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52   _____
53   Medication 7:
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57   Medication 8:
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59   _____
60   Medication 9:

                                                    _____

Medication 10:

_____

Birth Control Pills

Medication 1:

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Medication 2:

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Medication 3:

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Medication 4:

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Medication 5:

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Medication 6:

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Medication 7:

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Medication 8:

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Medication 9:

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Medication 10:

_____

Hormone replacement therapy

Medication 1:

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Medication 2:

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Medication 3:

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Medication 4:

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Medication 5:

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Medication 6:

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Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-hypertensives

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-convulsants

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____ _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Other

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Are any of the following substances currently being used/misused?

	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Opiates	○	○	○
Solvents	○	○	○
Crack/Cocaine	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following substance use/misuse treatments currently being accessed?

	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following currently being experienced?

	No	Yes	Unknown	To be followed up after clinic
Teachers assistants prior to diagnosis	○	○	○	○
School expulsion/suspension	○	○	○	○
Employment problems	○	○	○	○
Needs help living on own	○	○	○	○
Needs assisted or sheltered housing	○	○	○	○
Legal problems: Victim	○	○	○	○
Legal problems: Offender	○	○	○	○
Custody issues/family court	○	○	○	○
Special courts jail	○	○	○	○
Regular courts jail	○	○	○	○
Incarcerated	○	○	○	○

Which of the following recommendations were made?

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	No	Yes	Yes, but service not available
Coaching	○	○	○
Support (individual or group)	○	○	○
FASD Education	○	○	○
FASD Early intervention	○	○	○
Counselling support group	○	○	○
Counselling or individual therapy	○	○	○
Couple/family counselling	○	○	○
Substance abuse counselling/therapy	○	○	○
Respite	○	○	○
Sexual Health Education	○	○	○
Anger Management	○	○	○

	No	Yes	Yes, but service not available
Child protection	○	○	○
Spousal abuse intervention	○	○	○
Mental health support	○	○	○
Income support	○	○	○
Food bank	○	○	○
Emergency housing/shelter	○	○	○
Daycare	○	○	○
Guardianship	○	○	○
Power of Attorney	○	○	○
Personal directive	○	○	○

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	No	Yes	Yes, but service not available
Legal aid	○	○	○
Services for civil court issues	○	○	○
Services for family court issues	○	○	○
Speech and language pathologist	○	○	○
Behaviour Therapy services (CBT, ABA, IBI, and other BT supports)	○	○	○
Medication/psychopharmacology	○	○	○
Occupational therapy	○	○	○
Accommodations/adaptation in environment, expectations, supports used, or routine	○	○	○
Anticipatory Guidance/Prevention: for the purpose of increasing awareness and/or decreasing risk of potential future problems	○	○	○
Safety: Precautions to be taken or specific measures to deal with safety concerns	○	○	○
Reassessment	○	○	○
Other substitute decision-making options	○	○	○
Other legal services	○	○	○
Medical referral	○	○	○
FASD-specific intervention	○	○	○

RENSEIGNEMENTS DÉMOGRAPHIQUES ET CARACTÉRISTIQUES DES PATIENTS

Identification

Code de site

_____

Pays
- ○ Canada
- ○ Australie
- ○ Nouvelle-Zélande
- ○ États-Unis
- ○ Royaume-Uni
- ○ France
- ○ Autre

Veuillez préciser

_____

1 Province/Territoire

- ◯ AB
- ◯ CB
- ◯ MB
- ◯ NB
- ◯ NE
- ◯ TN
- ◯ TNO
- ◯ NU
- ◯ ON
- ◯ QC
- ◯ SK
- ◯ YK

Année du diagnostic

_____

Type de diagnostic:

- ◯ Une évaluation initiale
- ◯ Une réévaluation
- ◯ Un suivi

Date de la référence

Mois

- ◯ janvier
- ◯ février
- ◯ mars
- ◯ avril
- ◯ mai
- ◯ juin
- ◯ juillet
- ◯ août
- ◯ septembre
- ◯ octobre
- ◯ novembre
- ◯ décembre

Année

_____

Source de la référence

- ◯ Agence des services sociaux (par ex. agence de services à l'enfance et à la famille, agence de soutien communautaire)
- ◯ Recommandation médicale
- ◯ Système éducatif (par ex. école, garderie)
- ◯ Système judiciaire
- ◯ Auto-recommandation
- ◯ Recommandation de la famille (par ex. parents biologiques, adoptifs, famille d'accueil)
- ◯ Autre

Veuillez préciser

_____

1 Raison de la référence
2
3 Veuillez cocher tout ce qui s'applique
4
5 ☐ Problèmes de comportement
6 ☐ Difficultés d'apprentissage
7 ☐ Problèmes avec le système judiciaire
8 ☐ Retards de développement/délais en matière de stades de développement
9 ☐ Problèmes de vie adaptatifs
10 ☐ Exposition prénatale à l'alcool confirmée
11 ☐ Difficultés en matière d'aptitudes sociales
12 ☐ Difficultés d'autorégulation (par ex. nourriture, sommeil, sens)
13 ☐ Réévaluation
14 ☐ Suivi
15 ☐ Pour établir l'éligibilité pour un soutien (financier ou programmes de soutien au développement)
16 ☐ Autre
17
18 Veuillez préciser
19 _____
20
21 Est-ce qu'un outil de dépistage a été utilisé   ◯ Non   ◯ Oui
22 pour la référence?
23
24 Quel outil?
25
26 _____
27
28 Qui a effectué le dépistage?
29 _____
30
31
32 Date de l'évaluation multidisciplinaire
33
34 Mois   ◯ janvier
35   ◯ février
36   ◯ mars
37   ◯ avril
38   ◯ mai
39   ◯ juin
40   ◯ juillet
41   ◯ août
42   ◯ septembre
43   ◯ octobre
44   ◯ novembre
45   ◯ décembre
46
47 Année
48   _____
49
50 Sexe (biologique)   ◯ Homme   ◯ Femme
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52
53 Genre   ◯ Homme   ◯ Femme
54   ◯ Autre
55
56 Veuillez préciser
57   _____
58
59
60 Date de naissance

REDCap

Mois

- ○ janvier
- ○ février
- ○ mars
- ○ avril
- ○ mai
- ○ juin
- ○ juillet
- ○ août
- ○ septembre
- ○ octobre
- ○ novembre
- ○ décembre

Année

_____

Avec quel group ethnique cette personne s'identifie le plus?

- ☐ Caucasien
- ☐ Indigène
- ☐ Afro-Américain
- ☐ Latino-Américain
- ☐ Sud-Asiatique (p. ex. Indien de l'Inde, Pakistanais, Sri-Lankais, etc.)
- ☐ Asiatique occidental (p. ex. Iranien, Afghan, etc.)
- ☐ Chinois
- ☐ Philippin
- ☐ Coréen
- ☐ Japonais
- ☐ Asiatique du Sud-Est (p. ex. Vietnamien, Cambodgien, Laotien, Thaïlandais, etc.)
- ☐ Arabe
- ☐ Autre
- ☐ Inconnue

Veuillez préciser

_____

Situation domiciliaire

- ○ Indépendant
- ○ Avec mère biologique
- ○ Avec père biologique
- ○ Avec autre famille
- ○ Famille d'accueil (personnes qui ne font pas partie de la famille)
- ○ Parent(s) adoptif(s)
- ○ Foyer
- ○ Sans abri
- ○ En détention
- ○ Autre

Veuillez préciser autre famille

_____

Veuillez préciser

_____

Est-ce qu'un parent biologique a reçu un diagnostic de TSAF?

○ Non   ○ Oui   ○ Inconnue

Est-ce qu'un frère ou une soeur a reçu un diagnostic de TSAF

- ◯ Non
- ◯ Oui
- ◯ Inconnue
- ◯ Sans objet (enfant unique)

EVALUATION DE L'EXPOSITION PRÉNATALE À L'ALCOOL

L'exposition prénatale à l'alcool est:

- ◯ Absente (Confirmée)
- ◯ Présente (Confirmée)
- ◯ Non-confirmée
- ◯ Inconnue

Veuillez préciser la source, si connue

_____

Autres expositions prénatales

	Absente (Confirmée)	Présent (Confirmée)	Inconnue
Nicotine	◯	◯	◯
Opiacés	◯	◯	◯
Marijuana	◯	◯	◯
Cocaïne/crack	◯	◯	◯
Méthamphétamine/speed	◯	◯	◯
Médicaments prescrits	◯	◯	◯
Autre expositions	◯	◯	◯

Veuillez préciser

_____

Autres facteurs

Veuillez cocher tout ce qui s'applique

- ☐ Traumatisme post-natal
- ☐ Problèmes d'attachement
- ☐ Abus physique ou sexuel
- ☐ Autre

Veuillez préciser

_____

TRAITS FACIAUX CARACTÉRISTIQUES

Normes de fentes palpébrales utilisées:

- ☐ Normes canadiennes
- ☐ Thomas
- ☐ Scandinaves
- ☐ Autre

Veuillez préciser

_____

Longueur de la fente palpébrale

- ◯ >-1 ET
- ◯ > -2 ET & < -1 ET
- ◯ < -2 ET

Caractère lisse du philtrum	○ 1
	○ 2
Score sur le guide lip-philtrum	○ 3
	○ 4
	○ 5

Épaisseur de la lèvre supérieure	○ 1
	○ 2
score sur le guide Lip-philtrum	○ 3
	○ 4
	○ 5

Nombre total de traits faciaux caractéristiques présents	○ 0
	○ 1
	○ 2
	○ 3
	○ Non concluant

ÉVALUATION NEUROCOMPORTEMENTALE

Résultats de l'évaluation des domaines du cerveau

Veuillez indiquer si chaque domaine du cerveau a été évalvé

	Non Altéré	Altéré	Non évalué
Habiletés motrices	○	○	○
Neuroanatomie/Neurophysiologie	○	○	○
Cognition	○	○	○
Langage	○	○	○
Rendement scolaire	○	○	○
Mémoire	○	○	○
Attention	○	○	○
Fonction exécutive (y compris le contrôle des impulsions)	○	○	○
Régulation de l'affect	○	○	○
Comportement adaptatif, aptitudes sociales, ou communication sociale	○	○	○

QI global	○ Inférieur à 70
	○ 70
	○ 71-85
	○ Supérieur à 85
	○ Inconnu/non-calculé

Diagnostic	○ TSAF avec traits faciaux caractéristiques
	○ TSAF sans traits faciaux caractéristiques
	○ À risque de trouble neurodéveloppemental et de TSAF associés à l'exposition prénatale à l'alcool
	○ Pas de diagnostic de TSAF

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1			
2	Utilisez-vous un autre modèle de diagnostic pour enregistrer les informations (c.-à-d. le code diagnostique à 4 chiffres)?	◯ Non ◯ Oui	

Veuillez donner le code diagnostique à 4 chiffres

_____

Autres caractéristiques associées

Veuillez cocher tout ce qui s'applique

☐ Troubles du sommeil
☐ Sensibilités sensorielles
☐ Déficits de traitement sensoriel
☐ Traumatisme
☐ Vitesse de traitement réduite
☐ identité sexuelle
☐ Autre

Veuillez préciser

_____

Autre diagnostic

Remarque : L'évaluation n'avait pas à se produire à cette clinique spécifique.

	Non (Évalué)	Oui (Évalué et diagnostiqué)	Non évalué
Malformations congénitales	◯	◯	◯
Déficience intellectuelle	◯	◯	◯
TDA/TDAH	◯	◯	◯
Troubles d'attachement	◯	◯	◯
Dyspraxie	◯	◯	◯
Trouble/Déficience du langage	◯	◯	◯
Déficience auditive	◯	◯	◯
Déficience visuelle	◯	◯	◯
Maladie de Gilles de la Tourette	◯	◯	◯
Trouble anxieux	◯	◯	◯
Troubles du spectre autistique	◯	◯	◯
Trouble bipolaire	◯	◯	◯
Trouble de comportement	◯	◯	◯
Trouble de l'humeur	◯	◯	◯
Trouble obsessif compulsif	◯	◯	◯
Trouble de la personnalité	◯	◯	◯
TSPT	◯	◯	◯
Schizophrénie	◯	◯	◯
Trouble lié à l'abus d'alcool ou d'autres drogues	◯	◯	◯
Tentatives de suicide /idées suicidaires	◯	◯	◯

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1 Autres   ◯   ◯   ◯
2

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4 Veuillez préciser
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8 ANTÉCÉDENTS MÉDICAUX
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10 Retard de croissance   ◯ Non   ◯ Oui
11

12 _____
13 Veuillez préciser
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15 _____

16 Troubles neurologiques   ◯ Non   ◯ Oui
17

18 _____
19 Veuillez préciser
20   _____
21 _____

22 Problèmes de santé mentale   ◯ Non   ◯ Oui
23

24 _____
25 Veuillez préciser
26   _____
27 _____

27 Problèmes de tête et de cou   ◯ Non   ◯ Oui
28

29 _____
30 Veuillez préciser
31   _____
32 _____

33 Troubles cardiovasculaires   ◯ Non   ◯ Oui
34

35 _____
36 Veuillez préciser
37   _____
38 _____

38 Troubles du système respiratoire   ◯ Non   ◯ Oui
39

40 _____
41 Veuillez préciser
42   _____
43 _____

44 Troubles endocrinologiques   ◯ Non   ◯ Oui
45

46 _____
47 Veuillez préciser
48   _____
49 _____

50 Problèmes musculosquelettiques   ◯ Non   ◯ Oui
51

52 _____
53 Veuillez préciser
54   _____
55 _____

55 Maladies contagieuses   ◯ Non   ◯ Oui
56

57 _____
58 Veuillez préciser
59   _____
60 _____

Autres ◯ Non ◯ Oui

Veuillez préciser

_____

MÉDICAMENTS

	Non	Oui
Omega-3	◯	◯
Choline	◯	◯
Glutamine	◯	◯
Aripiprazole	◯	◯
Vortioxetine	◯	◯
Minocycline	◯	◯
Bupropion	◯	◯
Buspirone	◯	◯
Clozapine	◯	◯
Melatonin	◯	◯

Veuillez dresser une liste des autres médicaments consommés actuellement

Stimulants

Médicament 1: _____

Médicament 2: _____

Médicament 3: _____

Médicament 4: _____

Médicament 5: _____

Médicament 6: _____

Médicament 7: _____

Médicament 8: _____

Médicament 9: _____

Médicament 10:

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Antidépresseurs

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Antipsychotiques

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Pilule contraceptive

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Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Traitement hormonal substitutif

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Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 5:

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Médicament 9:

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Médicament 10:

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Antihypertenseurs

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Anticonvulsivants

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34   Autres
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60   Médicament 8:

                                                                                    _____

Médicament 9: _____

Médicament 10: _____

Est-ce que les substances suivantes sont présentement consommées/surconsommées?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Opiacés	○	○	○
Solvants	○	○	○
Crack/ cocaïne	○	○	○
Autres	○	○	○

Veuillez préciser _____

Est-ce que l'individu en cours d'évaluation poursuivit présentement un traitement concernant une substance consommée/surconsommée ?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Autres	○	○	○

Veuillez préciser _____

Est-ce que l'individu en cours d'évaluation se trouve dans une ou plusieurs des situations suivantes?

	Non	Oui	Inconnu	Suivi à effectuer après clinique
Aides enseignants avant le diagnostic	○	○	○	○
Expulsion/Suspension de l'école	○	○	○	○
Problèmes d'emploi	○	○	○	○
A besoin d'aide pour vivre seul	○	○	○	○
A besoin de logement protégé ou assisté	○	○	○	○
Problèmes juridiques : victime	○	○	○	○
Problèmes juridiques : accusé	○	○	○	○
Problèmes de garde/tribunal de la famille	○	○	○	○
Prison des tribunaux spéciaux	○	○	○	○
Prison des tribunaux réguliers	○	○	○	○
Incarcération	○	○	○	○

Lesquelles des recommandations suivantes ont été faites?

	Non	Oui	Service non-disponible
Encadrement	○	○	○
Soutien (individuel ou de groupe)	○	○	○
Stratégies de communication	○	○	○
Évaluation/Intervention précoce en matière de TSAF	○	○	○
Groupes de soutien/services de conseil	○	○	○
Services de conseils ou thérapie individuelle	○	○	○
Thérapie de couple/familiale	○	○	○
Services de conseils/thérapie en matière d'abus d'alcool ou de toxicomanie	○	○	○
Répit	○	○	○
Intervention contre la violence à l'égard des aînés	○	○	○

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	Non	Oui	Service non-disponible
Protection de l'enfance	○	○	○
Intervention contre la violence conjugale	○	○	○
Soutien en matière de santé mentale	○	○	○
Aide au revenu	○	○	○
Banque alimentaire	○	○	○
Logement/Abri d'urgence	○	○	○
Garderie	○	○	○
Tutelle	○	○	○
Procuration	○	○	○
Instructions personnelles	○	○	○

	Non	Oui	Service non-disponible
Aide juridique	○	○	○
Services pour les problèmes au tribunal civil	○	○	○
Services pour les problèmes au tribunal de la famille	○	○	○
Orthophoniste	○	○	○
services de thérapie du comportement (ABA/IBI et autres soutiens)	○	○	○
Médicaments/Psychopharmacologie	○	○	○
Ergothérapie	○	○	○
Logement/Adaptation en environnement, attentes, soutiens ou routine	○	○	○
Conseils de prévention et d'orientation: dans le but d'augmenter la sensibilisation et/ ou réduire les problèmes potentiels à venir	○	○	○
Sécurité : précautions à prendre ou mesures spécifiques pour gérer des inquiétudes en matière de sécurité	○	○	○
Réévaluation	○	○	○
Options de prise de décisions alternatives	○	○	○
Autres services juridiques	○	○	○
Autres références médicales	○	○	○

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Establishing a protocol for building a national database for Fetal Alcohol Spectrum Disorder diagnostic assessment-related information in Canada

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Establishing a protocol for building a national database for Fetal Alcohol Spectrum Disorder diagnostic assessment-related information in Canada

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ABSTRACT

Introduction: Fetal Alcohol Spectrum Disorder (FASD) is one of the most common neurodevelopmental

disorders in North America. It is a complex disability, associated with challenges in cognitive,

behavioural, and social-emotional functioning, as well as an increased risk of physical and mental health

comorbidities, and difficulties in daily living across the lifespan. Previous attempts to characterize the

profile of this population have been hampered by differences in data collected across studies, regional

discrepancies in terminology and definitions, and a lack of tools to integrate comprehensive datasets.

Methods and analysis: The goals of this study are to use the Canadian National FASD Database, a

national repository of FASD assessment-related information, to better understand the functional profile,

comorbidities, intervention needs, and difficulties in daily living experienced by individuals assessed for

FASD across the lifespan. We will also examine what factors may be the most sensitive predictors of

receiving an FASD diagnosis. Data will be analyzed from over 3,500 records collected between 2010 and

2021 (ongoing) from 26 FASD diagnostic clinics in seven provinces and territories. Data collection is

ongoing, and analysis will be performed on a bi-annual basis to continue to hone our understanding of

the profiles, needs, and outcomes of individuals assessed for FASD in Canada. This research is critical for

refining FASD assessment and diagnostic practice, enabling accurate and early identification of

individuals with FASD, and connecting individuals with FASD and their families to comprehensive and

effective services and resources to support healthy developmental trajectories. **Ethics and**

dissemination: Ethics approval for the National FASD Database Project was obtained from the Ottawa

Health Science Network Research Ethics Board. As new knowledge is gained from this project, findings

will be disseminated through publications, presentations, and feedback to participating clinics, with the

ultimate goal of informing FASD research, practice, and policy.

Key words: fetal alcohol spectrum disorder; prenatal alcohol exposure; assessment and diagnosis;

national database; developmental trajectories

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Strengths and limitations of this study

1. The Canadian National FASD Database is the first and only existing standardized patient-level database of individuals assessed for FASD in Canada, which allows for the identification of trends related to the prevalence and diagnosis of FASD and associated features.

2. Ongoing data collection enables the monitoring of changes in population-level profiles, needs, and experiences of individuals assessed for FASD in Canada, as well as access to timely information to guide FASD research, practice, and policy.

3. The Database was developed in consultation with governments, clinicians, researchers, and individuals with FASD and their families, ensuring that information collected is relevant and meaningful for individuals with FASD and those who support them.

4. Data is collected from many, but not all, clinics in Canada, and there are several provincial and territorial jurisdictions that are not represented in the Database.

5. Information collected is cross-sectional, limiting our ability to explore longitudinal trends or follow the developmental trajectories of individuals with FASD across the lifespan.

INTRODUCTION

Health and human development

Health vulnerability and associated developmental trajectories are rooted in the prenatal stage

and first years of life, both of which are critical periods involving complex interactions between

biological, genetic, and environmental conditions. Many determinants of health contribute to optimal

development and are relevant for all human beings, regardless of culture or background. Maternal and

fetal health, the early caregiving environment and family influences, poverty and malnutrition,

neighbourhood factors, and the broader socio-political context can all have profound impacts on human

development and healthy outcomes.[1] In the long term, poor physical, mental, and socioemotional

development in childhood is linked to unfavourable outcomes such as school failure, delinquency,

unemployment, and poor health in adulthood.[2]

Researchers have worked hard to identify permissive and protective factors that optimize

developmental outcomes, from preconception through to adulthood. The presence of a diagnosable

medical condition early in life can greatly impact an individual's health trajectory throughout the

lifespan.[3] Data strongly suggest that providing early interventions and supports can have protective

effects, mitigate difficulties in daily living, and provide a foundation for healthier trajectories.[4]

However, in order to achieve these benefits, it is essential that individuals who are at risk are accurately

identified and connected with appropriate and effective supports.

Developmental trajectories and prenatal alcohol exposure

Prenatal alcohol exposure (PAE) is associated with a broad range of neurodevelopmental and

behavioural needs which, without standardized mechanisms for identification, can be unaddressed.

When needs are not recognized, individuals with PAE can experience substantial challenges, and critical

opportunities for early interventions to improve outcomes for individuals and families may be missed.[5]

Indeed, researchers have shown that early identification is one of the most powerful factors to mitigate the lifelong adverse effects of PAE.[4, 6]

Because of the complex and heterogeneous consequences of PAE, a standardized data collection protocol using common data fields can be a powerful and comprehensive tool for understanding PAE and its associated impacts. At a national level, such a protocol allows for the large-scale examination of the neurodevelopmental effects of PAE, as well as the identification of other social and environmental factors that may influence outcomes for individuals with PAE. Moreover, it can improve our understanding of the supports, strategies, and interventions that may reduce challenges and optimize growth and potential for positive outcomes for individuals with PAE and their families.

Fetal Alcohol Spectrum Disorder

When the brain- and body-based impacts of PAE reach a clinical threshold, individuals may be diagnosed with Fetal Alcohol Spectrum Disorder (FASD).[7] FASD is a lifelong disability associated with difficulties in motor function, learning, memory, attention, communication, emotional regulation, and social skills. Individuals with FASD often require ongoing support with daily living and are at high risk for compromised developmental trajectories, stemming from the neurodevelopmental impacts of PAE, compounded by complex biopsychosocial factors and societal. Individuals with FASD often have extensive patterns of impairment with co-occurring physical and mental health conditions that influence their clinical presentation, treatment recommendations, and potential outcomes.[5, 8-10] They also often experience early[11] and ongoing environmental adversity[5, 6, 12] and disruption in the caregiving environment [13, 14] which can impact social, behavioural, and emotional development.[13, 15, 16] Difficulties with daily living are common among individuals with FASD, including problems with school and employment; independence and housing; mental health and substance use challenges; and interaction with the justice system.[5, 6] That said, there is very limited research that focuses on the strengths of individuals with FASD, and this is a critical gap in order to implement strengths-based

approaches and interventions. [17] For example, one study identified predictive factors that contribute

to success in occupational performance in youth and adults with FASD, [18] another small study

reported on factors that influence success in school, [19] and others have reported on factors that

contribute to positive outcomes among adults with FASD who are involved in the justice system.[20]

FASD affects approximately 4% of the Canadian population and is a complex social and public

health issue.[21, 22] Individuals with FASD are an exceptionally complex and heterogeneous group, and

there is a strong interest among researchers and clinicians in characterizing the profiles, needs, and

experiences of these individuals.[23, 24] However, there are challenges with characterizing individuals

with FASD, such as inconsistent definitions of the disability, varying diagnostic systems and approaches,

as well as the resource-intensive multidisciplinary diagnostic process itself. Attempts to compare data

across FASD studies have largely failed because of the discrepancies in these definitions and approaches.

These challenges highlight the potential utility of a consistent, nation-wide database to inform FASD

research, practice, and policy.

Measuring FASD at the population level in Canada

In Canada, there is a paucity of population-level information about individuals with PAE and

FASD, which is critical for building meaningful, cost-effective, and appropriately distributed

programming and interventions. Over the past decade, Canadian researchers have sought to address

this gap by working together to develop and contribute to a standardized database with a common set

of indicators. The Universal FASDataForm Project was initiated in 2010 in collaboration with Canadian

FASD diagnostic clinics to determine if standardized collection of assessment-related data was a

possibility, and then subsequently to generate the first clinical dataset for FASD, and identify trends and

modalities related to prevention, prevalence, and diagnosis of FASD.[25] The FASDataForm was revised

in 2015 to refine the process of collecting and comparing common data indicators, resulting in the

updated (and renamed) National FASD Database Project. The main purpose of the Database Project is to

capture information related to the assessment and diagnosis of FASD in Canada, including information on the physical and mental health needs, functional challenges, and difficulties in daily living experienced by individuals presenting for FASD assessment across the country.

In the current study, our goal is to investigate the profile and experiences of individuals assessed for FASD in Canada. Analysis of data from the Database will allow us to interpret and disseminate findings on characteristics, associated features, and experiences of individuals presenting for an FASD assessment. The study is guided by the following research questions:

1. *What is the neurodevelopmental profile of individuals assessed for FASD in Canada? How does it compare to profiles of individuals assessed for FASD in other countries?*

2. *What are the physical and mental health comorbidities associated with FASD? How do these rates compare to the general population?*

3. *What are the most sensitive predictive factors for an FASD diagnosis?*

   a. *Which non-diagnostic factors are the most strongly predictive of FASD?*

   b. *Which diagnostic and individual factors are the most strongly predictive of FASD?*

4. *What are the most common recommendations for interventions for individuals assessed for FASD?*

5. *What factors may contribute to or protect against the difficulties in daily living associated with FASD?*

METHODS AND ANALYSIS

Data source and variables

The National FASD Database is an ongoing data repository comprised of clinical and diagnostic findings for individuals of all ages presenting for an FASD assessment to participating clinics (n = 26) from seven provinces and territories in Canada. The Database contains responses from a 287-item bilingual (English or French) questionnaire, completed online through the RedCap platform, usually by

the clinic intake co-ordinator. Data fields are populated based on chart review of each individual who

has completed the FASD assessment process. The Database includes records generated over two

data collection periods between 2010 and 2021, with ongoing entry.

The Database captures a wide range of information including individual demographics, referral

source and reasons for referral, living situation, family history of FASD, prenatal exposure to alcohol and

other teratogens, and early life adversity. Aligning with the current Canadian Diagnostic Guideline

criteria,[7] data is recorded for each individual on confirmation of PAE above risk levels[i], measurement

of sentinel facial features (SFF)[ii], assessment of neurodevelopmental functioning in 10 domains[iii], and

FASD diagnostic outcome. Associated features of FASD are also recorded, as well as comprehensive

information about the client's physical and mental health, including comorbidities, medication,

substance use, and difficulties in daily living. Finally, data is collected on recommendations for

intervention, and on whether these recommended services are available near the client's home (see

Appendix 1 for full questionnaire, and Table 1 for data collected for this study).

Table 1. Data collected.

Demographics	Age; gender; living situation; region
Historical data	Prenatal exposure to other substances; family history of FASD; trauma; attachment issues; physical or sexual abuse
Diagnostic criteria	Confirmation of PAE; facial measurements; neurodevelopmental functioning
Diagnostic outcome	FASD with SFF; FASD without SFF; At Risk for Neurodevelopmental Disorder (NDD)/FASD; No FASD
Associated features	Sleep problems; sensory sensitivities; sensory processing issues; slow processing speed; gender identity issues
Physical health comorbidities	Congenital malformations; auditory deficit; visual deficit; growth restriction; failure to thrive; microcephaly; neurological conditions; head and neck issues; cleft lip/palate; cardiovascular conditions; respiratory problems; endocrinological condition; musculoskeletal condition; infectious disease

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[i] Under the Canadian Diagnostic Guideline, above-risk PAE threshold is defined as ≥7 standard drinks per week, or ≥2 episodes of drinking of ≥4 drinks on the same occasion. FASD with SFF may be diagnosed in the absence of confirmed above-risk PAE given the specificity of simultaneous presentation of three SFFs to PAE.
[ii] Palpebral fissure length ≥2 standard deviations below the mean (<3rd percentile), philtrum rated 4 or 5 on a 5-point scale of the University of Washington (UW) Lip-Philtrum Guide, upper lip rated 4 or 5 on a 5-point scale of the UW Guide.[1]
[iii] The 10 neurodevelopmental domains, as outlined in the Canadian Diagnostic Guideline, include: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication.

Mental health comorbidities	Intellectual disability; attention deficit hyperactivity disorder; attachment disorder; developmental coordination disorder; language disorder/impairment; Tourette syndrome; anxiety disorder; mood disorder; autism spectrum disorder; bipolar disorder; conduct disorder; oppositional defiant disorder; obsessive compulsive disorder; post-traumatic stress disorder; schizophrenia; substance use disorder; suicidality
Recommendations	Coaching or support; FASD-specific (education or intervention); counselling (support group, individual therapy, or couples/family); respite or daycare; substance use treatment; sexual health education; anger management; spousal abuse intervention; mental health support; basic needs (income support, food bank, safety precautions); guardianship, power of attorney, personal directive, or other substitute decision making; child protection; legal services (legal aid, services for civil or family court issues); allied health services (speech and language pathologist, occupational therapy, behaviour therapy); medication/psychopharmacology or medical referral; accommodations/adaptation in environment, expectations, supports, or routine; anticipatory guidance/prevention; reassessment
Difficulties in daily living	School problems (requiring teacher assistants, expulsion/suspension); employment problems; problems with living independently; housing problems (requiring assisted or sheltered housing); legal problems (victimization, offending, custody/family court issues, incarceration)

As of June 2021 the Database contained more than 3,500 records collected between 2010 and 2021. All individuals were evaluated by a multi-disciplinary team according to the Canadian Diagnostic Guidelines for FASD.[7] Of the individual records that included a diagnostic outcome, 62% received an FASD diagnosis (53% without SFF and 9% with SFF), and 11% were designated At-Risk of NDD/FASD. The mean age of individuals was 14 years old (range 0 to 60 years), and 59% of the sample identified as male.

Patient and public involvement

Anecdotally, patients, clinicians, and families want able to learn about FASD and its presentation with respect to brain impairment and physical and mental health comorbidities and, most importantly, bring a critical perspective to the work. The goal of this enhanced understanding is to inform more targeted and effective supports and services. Individuals with FASD want to know if their experiences are similar to the experiences of others with the same diagnosis, so they can contribute to the advancement of research.[26] Recognizing the valuable perspectives of individuals with FASD and their family members, as well as the clinical expertise of FASD diagnosticians, these stakeholders played an

integral role in the development and design of the National Database. Data fields in the Database and their indicators were developed by a rigorous process involving the input of diagnosticians and family members of those with FASD (the public), and adults with FASD (patients) across Canada and internationally. Feedback was sought from these stakeholders to ensure that data collection would be feasible and analysis would provide meaningful information and results.

Process of stakeholder engagement

In 2005, the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) administered a survey to their seven partner provinces and territories to identify current and future priorities for FASD-related research, projects, and programs. One of the top identified priority areas was multidisciplinary diagnostic clinics. In order to better understand the gaps and opportunities in this area, CanFASD hosted a National Forum and invited representatives from every FASD diagnostic clinic in Canada, parents who represented families with FASD, as well as senior researchers in the field of FASD diagnosis at the time. One hundred eighteen participants met over a two-day period for facilitated discussions and focussed on the following questions:

- In what ways can cross-regional networking of FASD clinical information enhance or advance clinical research and knowledge transfer?

- What are the potential conflicts of interest and solutions that need to be considered?

- How should data be managed and controlled? What issues must be considered in data collection, data transfer, data storage, data access, data usage, and data ownership?

- How can diagnostic clinics across Canada work together over the next six months to develop a process for a dataset that would be clinically relevant and helpful in knowledge transfer?

Forum participants identified a critical need for standardized data collection by FASD diagnostic clinics across Canada, based on the same norms and using the same set of neuropsychological tests across clinics. They concluded that having all Canadian clinics contribute to a common dataset would provide

an adequate sample size to develop Canadian norms for a measures with existing norms derived from

other countries (i.e., growth charts). It was also anticipated that a common dataset would lead to a

more accurate and helpful diagnostic system, including physical measures (dysmorphology), brain

images, and functional (psychometric) measures of the brain.

A working group was then developed to translate the recommendations of the National Forum

into a process for data collection. Working group members were invited by CanFASD, based on

experience and expertise in the field of FASD diagnosis. Members included paediatricians (n = 3), a

clinical geneticist (n = 1), social workers (n = 2), FASD diagnostic clinic coordinators (n = 4), psychologists

(n = 4), parents of individuals with FASD (n = 2), speech and language pathologists (n = 2), and FASD

researchers (n = 2). The group had representation from eastern, western, and central Canada and met in

person for four days over the course of one year (2006). From these meetings, datafields were

developed that were based upon the diagnostic criteria of the 2005 Canadian Guidelines for Diagnosis

[27] currently in use at that time. Each datafield was discussed individually and combined into a form,

which was streamlined as much as possible so as not to add undue burden to data entry personnel. The

ultimate goal of the form was to provide data that would:

- Be meaningful to FASD diagnostic clinics to help them better understand their population

  and to anticipate supports and services

- Be meaningful to individuals with FASD and their families to better understand their

  disability and to receive effective recommendations

- Contribute evidence to the FASD research field

- Help policy makers with information they need to advocate for and to implement policies,

  programs, and services related to FASD in their jurisdictions.

The form was piloted with two of Canada's largest diagnostic clinics who each used it for five

patients. Feedback from the pilot was incorporated into the form, and in 2007-2008 the form was sent

to every diagnostic clinic in Canada, along with a data dictionary and instructions. Clinics were contacted

to guage their interest and invited to an introductory teleconference with the working group. A

template for patient consent and for ethics application was also provided. Over the next four years,

clinics navigated the process of establishing datasets in their jurisdications with support by the working

group and by 2012, 307 forms were submitted by four provinces.

With publication of the updated FASD Diagnostic Guidelines in Canada [7], it became necessary

to update the datafields. The working group surveyed all clinics participating in data collection and

received feedback about the process and utility of the data collected (N=48 clinics responded). The

working group also shared the form and sought feedback from experts in the United States (N=4),

Australia (N=1), and New Zealand (N=2) who also had FASD data collection systems. The working group

met in person twice over the next year to refine the form as well as to identify an online platform for

data entry and hosting. Two in-person workshops (2 hours each) were hosted with participation from

families, individuals with FASD, clinicians, researchers, and clinic coordinators who were attending FASD

conferences and wished to attend (N=68). The focus of discussion during these workshops was on the

datafields and the process for data collection via the new online platform. Feedback was incorporated

by the working group, and the online "Dataform" was created in both English and French. An

information package was then sent to each diagnostic clinic in Canada (N=65) as well as a clinic code for

data entry and access to the online system.

A unique and important element of stakeholder engagement in this project was the involvement

of families (the public) and individuals with FASD (patients). These stakeholders participated extensively

in developing the datafields that comprise the Database, and helped to define the scope of the dataset,

especially related to recommendations. For example, adults with FASD reported that they wanted to

obtain more information on the trajectory of physical and mental health comorbidities across the

lifespan, and their specific requests were included as indicators. Clinics and families who participated in

the development of the Database also helped to define the project's research questions and will

continue to do so on an ongoing basis. Regular communication with clinics including conference calls,

annual face-to-face meetings, quarterly newsletters, and individual clinic updates allows for ongoing

collaboration, data quality assessment, and refinement of the data collection process. To ensure that

knowledge from the Database is translated meaningfully, feedback and data are provided on a bi-annual

basis to each participating clinic for their own use and comparison with provincial and national

aggregate datasets. Results are disseminated in a format that clinics can share with their patients and

families. Findings from the Database have also been (and will continue to be) presented at various

national and international meetings that are attended by individuals with FASD.

Data analysis plan

Statistical analyses will be performed bi-annually on datasets extracted in the fall (September

30) and spring (April 30) of each year, using SPSS Statistics 27 software. All data will be grouped

categorically. For demographic information, data will be coded as follows: age cohort (0-5 years, 6-12

years, 13-17 years, 18+ years), gender (male, female, other), living situation (independent, with

biological mother, biological father, other family member[s], foster care [non-family], adoptive

parent[s], group home, homeless, in custody, other), and region (Northern and Western Canada, the

Prairies, Central Canada, Atlantic Canada). For diagnostic criteria, confirmation of PAE will be coded as

present, absent, or unconfirmed/unknown; facial measurements will be coded as the number of SFF

present (0, 1, 2, 3, or inconclusive); neurodevelopmental functioning in each domain will be coded

dichotomously (significantly impaired vs. not significantly impaired); and diagnosis will be coded as one

of the four outcomes (FASD with SFF, FASD without SFF, At Risk for NDD/FASD, No FASD). All other data

will be coded dichotomously as either absent or present.

Descriptive statistics will be used to characterize the sample for categorical data. We will

conduct Pearson chi-square tests and logistic regression to compare patterns between groups, examine

predictive factors, and explore strengths of association. Where available, prevalence data (e.g.,

comorbidities) will be compared to rates found in neurotypical populations.

Research question 1

What is the neurodevelopmental profile of individuals assessed for FASD in Canada? How does it

compare to profiles of individuals assessed for FASD in other countries?

The neurodevelopmental profile of individuals assessed for FASD will be described in terms of

the frequencies and patterns of neurodevelopmental impairment, and associated difficulties. Profiles

will be compared between diagnostic outcomes, age cohorts, and genders. We will also examine the

patterns of each diagnostic criterion within diagnostic outcomes, age cohorts, and genders. Findings in

this area will provide valuable information about the profile of needs of individuals with FASD, and

improve our understanding of where interventions may be targeted to improve outcomes for individuals

with FASD. In addition, we will examine how the profile of neurodevelopmental needs in the Canadian

population of individuals assessed for FASD compares to that in other countries. This will be possible

through our established partnerships with FASD experts, researchers, and clinicians in Australia, the

United Kingdon, and the United States, all of whom have been working to develop their own national

FASD databases similar to that in Canada.

Research question 2

What are the physical and mental health comorbidities associated with FASD? How do these rates

compare to the general population?

The frequencies and patterns of health comorbidities among individuals assessed for FASD will

be examined, and compared across diagnostic outcomes, age cohorts, and genders. The strengths of

association will be examined between physical and mental health comorbidities and diagnostic

outcomes, pattern of brain impairment, and difficulties in daily living. This information will allow for a

more holistic and comprehensive understanding of the needs of individuals with FASD across the

lifespan and will uncover areas of difficulty that may warrant additional services and supports. To

compare the rates of co-occurring physical and mental health conditions in FASD with those in the

general population, we will utilize existing data published in the academic (e.g., [28,29]) and grey (e.g.,

[30]) literature.

Research question 3

A. Which non-diagnostic factors are the most strongly predictive of FASD?

With this question, we aim to identify the combinations of demographic, historical, physical and

mental health, and adversity factors that are most strongly associated with being diagnosed with FASD

for different age cohorts and genders. We will also explore the strengths of association between

predictive factors and FASD diagnosis (any FASD diagnosis and specific FASD diagnostic categories).

Predictive models will be developed to determine sensitivity and specificity of combinations of factors

associated with being diagnosed with FASD. It is anticipated that findings from these analyses will

further refine FASD diagnostic criteria, and lead to more sensitive screening tools across the life span.

B. Which diagnostic and individual factors are the most strongly predictive of FASD?

Diagnostic criteria data will be analysed collectively, independently, and interdependently to

explore which criteria may always co-occur, which are exclusive and predictive of FASD, and how non-

diagnostic factors including age, gender, history, or comorbidities may influence whether an individual

receives an FASD diagnosis.

Research question 4

What are the most common recommendations for interventions for individuals assessed for FASD?

The frequency and pattern of recommendations made for each diagnostic outcome, age cohort,

gender, and region will be examined. We will also explore whether and how different types of

recommendations are associated with specific areas of brain impairment and other physical and mental

health comorbidities. Recommendations will be compared across regions to develop intervention maps

for understanding what services are needed, and where they may be lacking. This information will allow

us to better understand practical areas where individuals with PAE require support across their lifespan,

and what factors influence the recommendations made. This information will be useful for clinicians to

influence policy and practice and advocate for consistency in service availability across the country.

Research question 5

What factors may contribute to or protect against the difficulties in daily living associated with FASD?

To explore this question, we will characterize and compare difficulties in daily living across

diagnostic outcomes, age cohorts, and genders. We will also examine the strengths of association

between difficulties in daily living and demographic and historical factors, diagnostic criteria,

comorbidities, and associated features. Although data in the Database is cross-sectional, this

examination will allow us to identify factors that may be related to difficulties in daily living across the

life span, and circumstances within which to introduce and optimize supports.

ETHICS AND DISSEMINATION

Ethics approval for this project was obtained from the Ottawa Health Science Network Research

Ethics Board (protocol # 20160423-0H1), and is renewed on an annual basis. The Database is hosted on

the secure RedCap platform at the University of Alberta, in Edmonton, Alberta, Canada. RedCap is an

important tool for data access, linkages, and mobilization. Upon agreeing to participate in the project,

clinics receive a random identification code, and the principal investigator and statistics team is blind to

the coding.

Researchers who wish to use the data for their own work are required to obtain approval from

their own institutional ethics boards, and apply to a Database oversight committee. Applications must

align with the intent and ethics of the overall project. On approval, an anonymised, aggregated dataset

is downloaded from the server and sent to the researchers via a secure, password-protected link. This

external use of data stimulates the development of new research questions and collaborations, and

expands the potential impact of the Database.

Several studies have been published from the Database[5, 25, 31] and many more are

underway. As new knowledge is gained, findings will be disseminated through presentations at local,

national, or international meetings; publications in academic and grey literature; and regular feedback

to participating clinics, all with the goal of informing FASD research, practice, and policy.

DISCUSSION

The National FASD Database provides rich information, both medical and behavioural, about

individuals assessed for FASD in Canada across the lifespan. This information contributes evidence

related to diagnostic criteria, determining the need for and availability of intervention supports, and

stimulating further research. Information collected in the Database will improve our understanding of

the challenges, clinical profiles, functional needs , and outcomes of Canadians who are exposed to

alcohol prenatally. We know that Canadians presenting at FASD clinics experience substantial difficulties

navigating daily life,[5] and continued data collection and analysis through the Database has important

implications for guiding practice and policy responses to improve quality of life for these individuals and

their families. The Database also captures important information about individuals who are assessed for

FASD but are not diagnosed. Although evidence in this area is limited, researchers suggest that clinically-

referred individuals with PAE who do not meet the criteria for a formal diagnosis may nonetheless

experience complex needs requiring timely care.[5,32] Information on the functional needs and complex

presentations of all Canadians with PAE allows for a comprehensive understanding of areas where

supports are needed, and guides efforts to provide the most appropriate services and interventions.

Collecting information from Canadians with PAE across the lifespan allows us to understand

more about the trajectory of FASD in Canada, whether the common experiences of Canadians with FASD

change systematically over time, and how services and policies should be modified to meet these

changing needs. The Database also allows us to compare the profiles and characteristics of Canadians

with FASD to other subgroups of the population to identify unique or pressing needs. Examining trends

in FASD data at a regional level will allow us to determine whether the needs of individuals with FASD

differ in specific locations, and whether tailored approaches to service delivery are needed and available

in different parts of the country. Similarly, findings from the Database Project will reveal important

information about the gaps between FASD diagnosis and service availability for families impacted by

FASD. Individuals with FASD and their caregivers require access to coordinated supports and services

that are informed by the pattern of brain impairment from the diagnostic assessment.[29] In the current

service system, these supports may be lacking, and findings from the Database will highlight the most

common recommendations, as well as the most significant gaps in FASD service provision.

Finally, the Database provides a structure for active communication and collaboration among all

clinics in Canada that provide FASD diagnostic services. Already, there is preliminary data to suggest that

FASD clinicians are operating with a good deal of consistency across the country,[33,34] which may in

part be attributable to engagement with the National Database. This coordinated approach allows for a

consistent application of FASD best practices, a cohesive community of practice, and a stronger network

of experts working together to support improved outcomes for individuals with FASD and their families.

Limitations and challenges

The Database Project has several limitations. First, despite our goal to have every diagnostic

clinic in Canada (approximately 60 to date) contributing to the Database, some jurisdictions are not

represented. We have made significant efforts to recruit clinics from every Canadian province and

territory, and to reduce barriers to participation, we continue to assist clinics with their local ethics

applications. Nonetheless, there are regional gaps in the data that limit nation-wide conclusions.

Second, because the information in the Database is cross-sectional, it is not possible to examine

longitudinal trends or to follow-up with individuals to see how their profiles and needs change

throughout their lifespan. However, because data is collected from individuals at various life stages,

general snapshot observations can be made about different experiences or challenges that may be most

relevant for individuals with FASD as they age. Relatedly, with this project, we will be able to identify

important focal points that warrant follow-up using longitudinal approaches to best understand this

population. In addition, since the Database is a clinical dataset rather than a true research database,

there is no control group of neurotypical individuals, or of individuals who have PAE but do not

experience problems significant enough to trigger a referral for assessment. Therefore, in order to

contextualize findings from the Database, we typically must compare results with existing literature

from neurotypical populations (e.g., prevalence of mental health disorders). Importantly, although the

Database provides a mechanism for uncovering areas of *relative* strength or absence of deficit among

individuals assessed for FASD, in future iterations of the Database we will consider more targeted

approaches and methods for identifying strengths-based characteristics, skills and assets that may be

leveraged to support positive outcomes in this population.

Additional limitations relate to the data collected on PAE. Currently, the Database does not

include information about amount or type of alcohol consumed, nor does it include the specific timing

of exposure during pregnancy. Moreover, although "confirmed absent" PAE refers to no alcohol

exposure, and confirmed PAE indicates exposure "at or above risk levels" as specified in the Canadian

Diagnostic Guideline [7], exposure levels between 'none' and 'above risk' are not captured. Most (if not

all) clinics only accept individuals for an assessment if they meet or exceed the minimum PAE threshold.

The legal, ethical, and administrative processing that is necessary to conduct research of this

scope across jurisdictional lines is possible, but arduous, and may limit the level of detail included in the

Database. A great deal of consideration was given to the development of each question, balancing the

need to derive meaningful information with the priority that data entry must not be burdensome for

clinics. However, through clinic consultation, we have learned that additional valuable information

would be available for collection in future iterations of the Database. For instance, although in-depth

information regarding the amount and timing of PAE was thought to be unattainable at the time of the

Database development, we have learned that most clinics have access to this information and that it

would be feasible to collect in the future.

Finally, although the Database is structured according to the Canadian FASD Diagnostic

Guideline,[7] and guidance is provided to clinics for measuring and reporting on the diagnostic criteria,

including a Data Dictionary, information in the Dataset still comes from numerous sources. These

include self-report, record review, or screening tools, and this variability may result in inconsistent

reporting. In order to mitigate this, participating clinics have been provided with a list of recommended

assessment tools for each of the measurements, where appropriate. Clinics also use a collaborative

online platform to share ideas and experiences related to data field interpretation and data entry, in

order to increase consistency in the use of the Database. Without funding for each clinic, it is necessary

to rely on the enthusiasm and investment of clinicians to sustain the partnership. Without the efforts of

the participating clinics and the individuals and families who consent to their data collection, the

Database would not be possible.

CONCLUSION

Canada's National FASD Database provides an important framework for characterizing and

exploring the needs and outcomes of individuals with PAE across the life span. The comprehensive and

nation-wide scope of the Database enables researchers to examine questions that have not previously

been possible to explore. The Database provides a unique and timely opportunity to monitor the

prevalence of FASD and associated health comorbidities at a population level, as well as evidence to

determine optimal interventions mapped to physical, mental, and neurodevelopmental issues and

optimize developmental trajectories of individuals prenatally exposed to alcohol. The clinical

presentation of Canadians with PAE and FASD is highly complex, and information derived from the

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Database provides direct evidence of areas where supports are needed. Critically, this information can

guide our efforts to provide the most appropriate services and interventions to support positive

outcomes for individuals with FASD, their caregivers, families, and communities.

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AUTHORS' CONTRIBUTIONS

J Cook lead the conceptualization of the design of this project, the applications for funding and the overall development of the database. K Unsworth lead the recruitment of participants and clinics, development of the knowledge translation plan and the reporting of the work. K Flannigan refined research questions, piloted the survey tool and provided interpretation of the data. All authors drafted sections of the manuscript and revised it critically. All approve this final version for publication and agree to be accountable for all aspects of the work.

COMPETING INTERESTS STATEMENT

None to declare.

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CanFASD Dataform

1
2
3
4
5 Preferred language/Langue de préférence: ◯ English   ◯ Français
6
7
8
9 DEMOGRAPHIC INFORMATION AND PATIENT CHARACTERISTICS
10
11
12 Identification
13
14 Site ID
15
16 _____
17
18 Country   ◯ Canada
19   ◯ Australia
20   ◯ New Zealand
21   ◯ United States
22   ◯ United Kingdom
23   ◯ France
24   ◯ Other
25
26 Please specify
27   _____
28
29 Province/Territory   ◯ AB
30   ◯ BC
31   ◯ MB
32   ◯ NB
33   ◯ NS
34   ◯ NL
35   ◯ NWT
36   ◯ NU
37   ◯ ON
38   ◯ QC
39   ◯ SK
40   ◯ YK
41
42 Type of assessment   ◯ Initial Assessment
43   ◯ Re-assessment
44   ◯ Follow-up
45
46 If being re-assessed, was the individual previously   ◯ Yes
47 given an "At Risk" designation?   ◯ No
48   ◯ Unknown
49
50
51 Date of Referral
52
53
54
55
56
57
58
59
60

REDCap

1	Month	◯ January
2		◯ February
3		◯ March
4		◯ April
5		◯ May
6		◯ June
7		◯ July
8		◯ August
9		◯ September
10		◯ October
11		◯ November
12		◯ December

Year

_____

Source of Referral

◯ Social Services Agency (e.g., Child and Family Services agency, community support agency)
◯ Medical Referral
◯ Education System (e.g., school, daycare)
◯ Legal System
◯ Self
◯ Family referral (e.g., biological, foster, adoptive parent)
◯ Other

Specify

_____

Reason(s) for referral

Please check all that apply

☐ Behavioural issues
☐ Learning difficulties
☐ Difficulties with the law
☐ Developmental delays/delays to meet developmental milestones
☐ Adaptive living problems
☐ Confirmed prenatal alcohol exposure
☐ Social skills difficulties
☐ Self-regulation difficulties (feeding, sleeping, sensory)
☐ Reassessment
☐ Follow-up
☐ Establish eligibility for supports (e.g., financial or developmental support programs)
☐ Other

Please specify

_____

Was a screening tool used for referral?   ◯ No   ◯ Yes

Which tool?

_____

Who did the screen?

_____

Date of Diagnostic Assessment

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

| Year | _____ |

| Sex | ○ Male   ○ Female |

| Gender identity | ○ Male   ○ Female   ○ Other |

| Please specify | _____ |

Date of Birth

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

| Year | _____ |

Which ethnic group(s) does this person most identify with?

- ☐ Caucasian
- ☐ Indigenous
- ☐ African American
- ☐ Latin American
- ☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
- ☐ West Asian (e.g. Iranian, Afghan, etc.)
- ☐ Chinese
- ☐ Filipino
- ☐ Korean
- ☐ Japanese
- ☐ Southeast Asian (e.g. Vietnamese, Cambodia, Laotian, Thai, etc.)
- ☐ Arab
- ☐ Other
- ☐ Unknown

Specify

_____

Current living situation

- ○ Independent
- ○ With biological mother
- ○ With biological father
- ○ With other family member(s)
- ○ Foster care (non-family member)
- ○ Adoptive parent(s)
- ○ Group home
- ○ Homeless
- ○ In custody
- ○ Other

Specify other family member(s)

_____

Specify

_____

Has a biological parent been diagnosed with FASD?   ○ No   ○ Yes   ○ Unknown

Has a sibling been diagnosed with FASD?
- ○ No
- ○ Yes
- ○ Unknown
- ○ Not applicable (no siblings)

ASSESSMENT OF PRENATAL ALCOHOL EXPOSURE

Prenatal alcohol exposure is:
- ○ Absent (Confirmed)
- ○ Present (Confirmed)
- ○ Unconfirmed
- ○ Unknown

Please specify source, if known

_____

Other prenatal exposures:

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	Absent (Confirmed)	Present (Confirmed)	Unknown
Nicotine	◯	◯	◯
Opiates	◯	◯	◯
Marijuana/cannabis	◯	◯	◯
Cocaine/crack	◯	◯	◯
Methamphetamine/speed	◯	◯	◯
Prescription medications	◯	◯	◯
Other Exposures	◯	◯	◯

Please specify

_____

Other factors

Please check all that apply

☐ Post-natal trauma
☐ Attachment issues
☐ Sexual or physical abuse
☐ Other

Please specify

_____

SENTINEL FACIAL FEATURES

Palpebral fissure norms used:

☐ Canadian norms
☐ Thomas
☐ Scandinavian
☐ Other

Please specify

_____

Palpebral fissure length

◯ >-1 SD
◯ > -2 SD & < -1 SD
◯ < -2 SD

Philtrum smoothness

Score on lip-philtrum guide

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5

Upper lip thinness

Score on lip-philtrum guide

◯ 1
◯ 2
◯ 3
◯ 4
◯ 5

Total number of sentinel facial features present

◯ 0
◯ 1
◯ 2
◯ 3
◯ Inconclusive

NEUROBEHAVIOURAL ASSESSMENT

Brain Domain Assessment Results

Please indicate how the following brain domain was assessed

	Not impaired	Significant Impairment	Not Assessed	Incomplete
Motor skills	○	○	○	○
Neuroanatomy/Neurophysiology	○	○	○	○
Cognition	○	○	○	○
Language	○	○	○	○
Academic achievement	○	○	○	○
Memory	○	○	○	○
Attention	○	○	○	○
Executive function including impulse control	○	○	○	○
Affect Regulation	○	○	○	○
Adaptive behaviour, social skills, or social communication	○	○	○	○

Full scale IQ
- ○ Less than 70
- ○ 70
- ○ 71-85
- ○ greater than 85
- ○ Unable to calculate

Diagnosis
- ○ FASD with sentinel facial features
- ○ FASD without sentinel facial features
- ○ At risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure
- ○ No FASD Diagnosis

Do you use another diagnostic schema to record information (i.e. 4-digit code)?   ○ No   ○ Yes

Please provide the 4-digit diagnostic code

_____

Other associated features

Please check all that apply
- ☐ Sleep problems
- ☐ Sensory sensitives
- ☐ Sensory processing
- ☐ Trauma
- ☐ Slower processing speed
- ☐ Gender identity
- ☐ Other

Please specify

_____

Other diagnoses

Note: Assessment did not have to occur at this clinic.

	No (Assessed but not diagnosed)	Yes (Assessed and diagnosed)	Not assessed
Congenital malformations	○	○	○
Intellectual disability	○	○	○
ADD/ADHD	○	○	○
Attachment disorder	○	○	○
Developmental coordination disorder	○	○	○
Language disorder/impairment	○	○	○
Auditory deficit	○	○	○
Visual deficit	○	○	○
Tourette's	○	○	○
Anxiety disorder	○	○	○
Autism Spectrum Disorders	○	○	○
Bipolar disorder	○	○	○
Conduct disorder	○	○	○
Mood disorder	○	○	○
Obsessive compulsive disorder	○	○	○
Personality disorder	○	○	○
PTSD	○	○	○
Schizophrenia	○	○	○
Substance abuse disorder	○	○	○
Suicide attempt(s)/Ideation	○	○	○
Oppositional defiant disorder	○	○	○
Other	○	○	○

Please specify

_____

MEDICAL HEALTH HISTORY

Growth restriction   ○ No   ○ Yes

Please specify height and weight percentiles

_____

Microcephaly   ○ Yes   ○ No

Failure to thrive   ○ yes   ○ No

Neurological conditions   ○ No   ○ Yes

Please specify

_____

Mental health   ○ No   ○ Yes

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Please specify

_____

Head and neck issues   ○ No   ○ Yes

Please specify

_____

Cleft Lip Palate   ○ Yes   ○ No

Cardiovascular conditions   ○ No   ○ Yes

Please specify

_____

Respiratory system   ○ No   ○ Yes

Please specify

_____

Endocrinological conditions   ○ No   ○ Yes

Please specify

_____

Musculoskeletal   ○ No   ○ Yes

Please specify

_____

Infectious diseases   ○ No   ○ Yes

Please specify

_____

Other   ○ No   ○ Yes

Please specify

_____

MEDICATION

	No	Yes
Omega-3	◯	◯
Choline	◯	◯
Glutamine	◯	◯
Aripiprazole	◯	◯
Vortioxetine	◯	◯
Minocycline	◯	◯
Bupropion	◯	◯
Buspirone	◯	◯
Clozapine	◯	◯
Melatonin	◯	◯

Please list all other current medications

Stimulants

Medication 1:
_____

Medication 2:
_____

Medication 3:
_____

Medication 4:
_____

Medication 5:
_____

Medication 6:
_____

Medication 7:
_____

Medication 8:
_____

Medication 9:
_____

Medication 10:
_____

Anti-depressants

Medication 1:
_____

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Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7:

_____

Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Anti-psychotics

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7:

_____

Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Birth Control Pills

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7:

_____

Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Hormone replacement therapy

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

1
2   Medication 7:
3   _____

4
5   Medication 8:
6   _____

7
8   Medication 9:
9
10   _____

11   Medication 10:
12
13   _____

14
15 Anti-hypertensives

16
17   Medication 1:
18
19   _____

20   Medication 2:
21
22   _____

23
24   Medication 3:
25
26   _____

27   Medication 4:
28
29   _____

30   Medication 5:
31
32   _____

33   Medication 6:
34
35   _____

36
37   Medication 7:
38
39   _____

40   Medication 8:
41
42   _____

43   Medication 9:
44
45   _____

46
47   Medication 10:
48
49   _____

50 Anti-convulsants
51
52   Medication 1:
53
54   _____

55
56   Medication 2:
57
58   _____

59   Medication 3:
60   _____

BMJ Open

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7:

_____

Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Other

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7:

_____

Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Are any of the following substances currently being used/misused?

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	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Opiates	○	○	○
Solvents	○	○	○
Crack/Cocaine	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following substance use/misuse treatments currently being accessed?

	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following currently being experienced?

	No	Yes	Unknown	To be followed up after clinic
Teachers assistants prior to diagnosis	○	○	○	○
School expulsion/suspension	○	○	○	○
Employment problems	○	○	○	○
Needs help living on own	○	○	○	○
Needs assisted or sheltered housing	○	○	○	○
Legal problems: Victim	○	○	○	○
Legal problems: Offender	○	○	○	○
Custody issues/family court	○	○	○	○
Special courts jail	○	○	○	○
Regular courts jail	○	○	○	○
Incarcerated	○	○	○	○

Which of the following recommendations were made?

	No	Yes	Yes, but service not available
Coaching	○	○	○
Support (individual or group)	○	○	○
FASD Education	○	○	○
FASD Early intervention	○	○	○
Counselling support group	○	○	○
Counselling or individual therapy	○	○	○
Couple/family counselling	○	○	○
Substance abuse counselling/therapy	○	○	○
Respite	○	○	○
Sexual Health Education	○	○	○
Anger Management	○	○	○

	No	Yes	Yes, but service not available
Child protection	○	○	○
Spousal abuse intervention	○	○	○
Mental health support	○	○	○
Income support	○	○	○
Food bank	○	○	○
Emergency housing/shelter	○	○	○
Daycare	○	○	○
Guardianship	○	○	○
Power of Attorney	○	○	○
Personal directive	○	○	○

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	No	Yes	Yes, but service not available
Legal aid	○	○	○
Services for civil court issues	○	○	○
Services for family court issues	○	○	○
Speech and language pathologist	○	○	○
Behaviour Therapy services (CBT, ABA, IBI, and other BT supports)	○	○	○
Medication/psychopharmacology	○	○	○
Occupational therapy	○	○	○
Accommodations/adaptation in environment, expectations, supports used, or routine	○	○	○
Anticipatory Guidance/Prevention: for the purpose of increasing awareness and/or decreasing risk of potential future problems	○	○	○
Safety: Precautions to be taken or specific measures to deal with safety concerns	○	○	○
Reassessment	○	○	○
Other substitute decision-making options	○	○	○
Other legal services	○	○	○
Medical referral	○	○	○
FASD-specific intervention	○	○	○

RENSEIGNEMENTS DÉMOGRAPHIQUES ET CARACTÉRISTIQUES DES PATIENTS

Identification

Code de site

_____

Pays

○ Canada
○ Australie
○ Nouvelle-Zélande
○ États-Unis
○ Royaume-Uni
○ France
○ Autre

Veuillez préciser

_____

Province/Territoire	◯ AB
	◯ CB
	◯ MB
	◯ NB
	◯ NE
	◯ TN
	◯ TNO
	◯ NU
	◯ ON
	◯ QC
	◯ SK
	◯ YK

Année du diagnostic

_____

Type de diagnostic:	◯ Une évaluation initiale
	◯ Une réévaluation
	◯ Un suivi

Date de la référence

Mois	◯ janvier
	◯ février
	◯ mars
	◯ avril
	◯ mai
	◯ juin
	◯ juillet
	◯ août
	◯ septembre
	◯ octobre
	◯ novembre
	◯ décembre

Année

_____

Source de la référence	◯ Agence des services sociaux (par ex. agence de services à l'enfance et à la famille, agence de soutien communautaire)
	◯ Recommandation médicale
	◯ Système éducatif (par ex. école, garderie)
	◯ Système judiciaire
	◯ Auto-recommandation
	◯ Recommandation de la famille (par ex. parents biologiques, adoptifs, famille d'accueil)
	◯ Autre

Veuillez préciser

_____

Raison de la référence

Veuillez cocher tout ce qui s'applique

☐ Problèmes de comportement
☐ Difficultés d'apprentissage
☐ Problèmes avec le système judiciaire
☐ Retards de développement/délais en matière de stades de développement
☐ Problèmes de vie adaptatifs
☐ Exposition prénatale à l'alcool confirmée
☐ Difficultés en matière d'aptitudes sociales
☐ Difficultés d'autorégulation (par ex. nourriture, sommeil, sens)
☐ Réévaluation
☐ Suivi
☐ Pour établir l'éligibilité pour un soutien (financier ou programmes de soutien au développement)
☐ Autre

Veuillez préciser

_____

Est-ce qu'un outil de dépistage a été utilisé
pour la référence?   ◯ Non   ◯ Oui

Quel outil?

_____

Qui a effectué le dépistage?

_____

Date de l'évaluation multidisciplinaire

Mois   ◯ janvier
                                        ◯ février
                                        ◯ mars
                                        ◯ avril
                                        ◯ mai
                                        ◯ juin
                                        ◯ juillet
                                        ◯ août
                                        ◯ septembre
                                        ◯ octobre
                                        ◯ novembre
                                        ◯ décembre

Année

_____

Sexe (biologique)   ◯ Homme   ◯ Femme

Genre   ◯ Homme   ◯ Femme
                                        ◯ Autre

Veuillez préciser

_____

Date de naissance

Mois

- ○ janvier
- ○ février
- ○ mars
- ○ avril
- ○ mai
- ○ juin
- ○ juillet
- ○ août
- ○ septembre
- ○ octobre
- ○ novembre
- ○ décembre

Année

_____

Avec quel group ethnique cette personne s'identifie le plus?

- ☐ Caucasien
- ☐ Indigène
- ☐ Afro-Américain
- ☐ Latino-Américain
- ☐ Sud-Asiatique (p. ex. Indien de l'Inde, Pakistanais, Sri-Lankais, etc.)
- ☐ Asiatique occidental (p. ex. Iranien, Afghan, etc.)
- ☐ Chinois
- ☐ Philippin
- ☐ Coréen
- ☐ Japonais
- ☐ Asiatique du Sud-Est (p. ex. Vietnamien, Cambodgien, Laotien, Thaïlandais, etc.)
- ☐ Arabe
- ☐ Autre
- ☐ Inconnue

Veuillez préciser

_____

Situation domiciliaire

- ○ Indépendant
- ○ Avec mère biologique
- ○ Avec père biologique
- ○ Avec autre famille
- ○ Famille d'accueil (personnes qui ne font pas partie de la famille)
- ○ Parent(s) adoptif(s)
- ○ Foyer
- ○ Sans abri
- ○ En détention
- ○ Autre

Veuillez préciser autre famille

_____

Veuillez préciser

_____

Est-ce qu'un parent biologique a reçu un diagnostic de TSAF?   ○ Non   ○ Oui   ○ Inconnue

Est-ce qu'un frère ou une soeur a reçu un diagnostic de TSAF

- ◯ Non
- ◯ Oui
- ◯ Inconnue
- ◯ Sans objet (enfant unique)

EVALUATION DE L'EXPOSITION PRÉNATALE À L'ALCOOL

L'exposition prénatale à l'alcool est:

- ◯ Absente (Confirmée)
- ◯ Présente (Confirmée)
- ◯ Non-confirmée
- ◯ Inconnue

Veuillez préciser la source, si connue

_____

Autres expositions prénatales

	Absente (Confirmée)	Présent (Confirmée)	Inconnue
Nicotine	◯	◯	◯
Opiacés	◯	◯	◯
Marijuana	◯	◯	◯
Cocaïne/crack	◯	◯	◯
Méthamphétamine/speed	◯	◯	◯
Médicaments prescrits	◯	◯	◯
Autre expositions	◯	◯	◯

Veuillez préciser

_____

Autres facteurs

Veuillez cocher tout ce qui s'applique

- ☐ Traumatisme post-natal
- ☐ Problèmes d'attachement
- ☐ Abus physique ou sexuel
- ☐ Autre

Veuillez préciser

_____

TRAITS FACIAUX CARACTÉRISTIQUES

Normes de fentes palpébrales utilisées:

- ☐ Normes canadiennes
- ☐ Thomas
- ☐ Scandinaves
- ☐ Autre

Veuillez préciser

_____

Longueur de la fente palpébrale

- ◯ >-1 ET
- ◯ > -2 ET & < -1 ET
- ◯ < -2 ET

Caractère lisse du philtrum

○ 1
○ 2
○ 3
○ 4
○ 5

Score sur le guide lip-philtrum

Épaisseur de la lèvre supérieure

○ 1
○ 2
○ 3
○ 4
○ 5

score sur le guide Lip-philtrum

Nombre total de traits faciaux caractéristiques présents

○ 0
○ 1
○ 2
○ 3
○ Non concluant

ÉVALUATION NEUROCOMPORTEMENTALE

Résultats de l'évaluation des domaines du cerveau

Veuillez indiquer si chaque domaine du cerveau a été évalvé

	Non Altéré	Altéré	Non évalué
Habiletés motrices	○	○	○
Neuroanatomie/Neurophysiologie	○	○	○
Cognition	○	○	○
Langage	○	○	○
Rendement scolaire	○	○	○
Mémoire	○	○	○
Attention	○	○	○
Fonction exécutive (y compris le contrôle des impulsions)	○	○	○
Régulation de l'affect	○	○	○
Comportement adaptatif, aptitudes sociales, ou communication sociale	○	○	○

QI global

○ Inférieur à 70
○ 70
○ 71-85
○ Supérieur à 85
○ Inconnu/non-calculé

Diagnostic

○ TSAF avec traits faciaux caractéristiques
○ TSAF sans traits faciaux caractéristiques
○ À risque de trouble neurodéveloppemental et de TSAF associés à l'exposition prénatale à l'alcool
○ Pas de diagnostic de TSAF

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Utilisez-vous un autre modèle de diagnostic pour enregistrer les informations (c.-à-d. le code diagnostique à 4 chiffres)?	◯ Non ◯ Oui	

Veuillez donner le code diagnostique à 4 chiffres

_____

Autres caractéristiques associées

Veuillez cocher tout ce qui s'applique

☐ Troubles du sommeil
☐ Sensibilités sensorielles
☐ Déficits de traitement sensoriel
☐ Traumatisme
☐ Vitesse de traitement réduite
☐ identité sexuelle
☐ Autre

Veuillez préciser

_____

Autre diagnostic

Remarque : L'évaluation n'avait pas à se produire à cette clinique spécifique.

	Non (Évalué)	Oui (Évalué et diagnostiqué)	Non évalué
Malformations congénitales	◯	◯	◯
Déficience intellectuelle	◯	◯	◯
TDA/TDAH	◯	◯	◯
Troubles d'attachement	◯	◯	◯
Dyspraxie	◯	◯	◯
Trouble/Déficience du langage	◯	◯	◯
Déficience auditive	◯	◯	◯
Déficience visuelle	◯	◯	◯
Maladie de Gilles de la Tourette	◯	◯	◯
Trouble anxieux	◯	◯	◯
Troubles du spectre autistique	◯	◯	◯
Trouble bipolaire	◯	◯	◯
Trouble de comportement	◯	◯	◯
Trouble de l'humeur	◯	◯	◯
Trouble obsessif compulsif	◯	◯	◯
Trouble de la personnalité	◯	◯	◯
TSPT	◯	◯	◯
Schizophrénie	◯	◯	◯
Trouble lié à l'abus d'alcool ou d'autres drogues	◯	◯	◯
Tentatives de suicide /idées suicidaires	◯	◯	◯

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1 Autres   ○   ○   ○
2
3 _____
4 Veuillez préciser
5   _____
6 _____
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8 ANTÉCÉDENTS MÉDICAUX
9
10 Retard de croissance   ○ Non   ○ Oui
11 _____
12 Veuillez préciser
13   _____
14 _____
15 _____
16 Troubles neurologiques   ○ Non   ○ Oui
17 _____
18 Veuillez préciser
19   _____
20 _____
21 _____
22 Problèmes de santé mentale   ○ Non   ○ Oui
23 _____
24 Veuillez préciser
25   _____
26 _____
27 Problèmes de tête et de cou   ○ Non   ○ Oui
28 _____
29 Veuillez préciser
30   _____
31 _____
32 _____
33 Troubles cardiovasculaires   ○ Non   ○ Oui
34 _____
35 Veuillez préciser
36   _____
37 _____
38 _____
39 Troubles du système respiratoire   ○ Non   ○ Oui
40 _____
41 Veuillez préciser
42   _____
43 _____
44 Troubles endocrinologiques   ○ Non   ○ Oui
45 _____
46 Veuillez préciser
47   _____
48 _____
49 _____
50 Problèmes musculosquelettiques   ○ Non   ○ Oui
51 _____
52 Veuillez préciser
53   _____
54 _____
55 _____
56 Maladies contagieuses   ○ Non   ○ Oui
57 _____
58 Veuillez préciser
59   _____
60 _____

	Non	Oui
Autres	○	○

Veuillez préciser

_____

MÉDICAMENTS

	Non	Oui
Omega-3	○	○
Choline	○	○
Glutamine	○	○
Aripiprazole	○	○
Vortioxetine	○	○
Minocycline	○	○
Bupropion	○	○
Buspirone	○	○
Clozapine	○	○
Melatonin	○	○

Veuillez dresser une liste des autres médicaments consommés actuellement

Stimulants

Médicament 1: _____

Médicament 2: _____

Médicament 3: _____

Médicament 4: _____

Médicament 5: _____

Médicament 6: _____

Médicament 7: _____

Médicament 8: _____

Médicament 9: _____

Médicament 10:

_____

Antidépresseurs

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Antipsychotiques

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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9   _____
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11   Médicament 10:
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13   _____
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15   Pilule contraceptive
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17   Médicament 1:
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19   _____
20   Médicament 2:
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23   Médicament 3:
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47   Médicament 10:
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49   _____
50   Traitement hormonal substitutif
51
52   Médicament 1:
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25 Antihypertenseurs
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27 Médicament 1:
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60 Anticonvulsivants

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Médicament 9:

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Médicament 10:

_____

Est-ce que les substances suivantes sont présentement consommées/surconsommées?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Opiacés	○	○	○
Solvants	○	○	○
Crack/ cocaïne	○	○	○
Autres	○	○	○

Veuillez préciser

_____

Est-ce que l'individu en cours d'évaluation poursuivit présentement un traitement concernant une substance consommée/surconsommée ?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Autres	○	○	○

Veuillez préciser

_____

Est-ce que l'individu en cours d'évaluation se trouve dans une ou plusieurs des situations suivantes?

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	Non	Oui	Inconnu	Suivi à effectuer après clinique
Aides enseignants avant le diagnostic	○	○	○	○
Expulsion/Suspension de l'école	○	○	○	○
Problèmes d'emploi	○	○	○	○
A besoin d'aide pour vivre seul	○	○	○	○
A besoin de logement protégé ou assisté	○	○	○	○
Problèmes juridiques : victime	○	○	○	○
Problèmes juridiques : accusé	○	○	○	○
Problèmes de garde/tribunal de la famille	○	○	○	○
Prison des tribunaux spéciaux	○	○	○	○
Prison des tribunaux réguliers	○	○	○	○
Incarcération	○	○	○	○

Lesquelles des recommandations suivantes ont été faites?

	Non	Oui	Service non-disponible
Encadrement	○	○	○
Soutien (individuel ou de groupe)	○	○	○
Stratégies de communication	○	○	○
Évaluation/Intervention précoce en matière de TSAF	○	○	○
Groupes de soutien/services de conseil	○	○	○
Services de conseils ou thérapie individuelle	○	○	○
Thérapie de couple/familiale	○	○	○
Services de conseils/thérapie en matière d'abus d'alcool ou de toxicomanie	○	○	○
Répit	○	○	○
Intervention contre la violence à l'égard des aînés	○	○	○

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	Non	Oui	Service non-disponible
Protection de l'enfance	○	○	○
Intervention contre la violence conjugale	○	○	○
Soutien en matière de santé mentale	○	○	○
Aide au revenu	○	○	○
Banque alimentaire	○	○	○
Logement/Abri d'urgence	○	○	○
Garderie	○	○	○
Tutelle	○	○	○
Procuration	○	○	○
Instructions personnelles	○	○	○

	Non	Oui	Service non-disponible
Aide juridique	○	○	○
Services pour les problèmes au tribunal civil	○	○	○
Services pour les problèmes au tribunal de la famille	○	○	○
Orthophoniste	○	○	○
services de thérapie du comportement (ABA/IBI et autres soutiens)	○	○	○
Médicaments/Psychopharmacologie	○	○	○
Ergothérapie	○	○	○
Logement/Adaptation en environnement, attentes, soutiens ou routine	○	○	○
Conseils de prévention et d'orientation: dans le but d'augmenter la sensibilisation et/ ou réduire les problèmes potentiels à venir	○	○	○
Sécurité : précautions à prendre ou mesures spécifiques pour gérer des inquiétudes en matière de sécurité	○	○	○
Réévaluation	○	○	○
Options de prise de décisions alternatives	○	○	○
Autres services juridiques	○	○	○
Autres références médicales	○	○	○

BMJ Open

Characterizing Fetal Acohol Spectrum Disorder in Canada: A national database protocol study

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Keywords:	Fetal medicine < OBSTETRICS, Developmental neurology & neurodisability < PAEDIATRICS, PUBLIC HEALTH, Substance misuse < PSYCHIATRY

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Characterizing Fetal Acohol Spectrum Disorder in Canada: A national database protocol study

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ABSTRACT

Introduction: Fetal Alcohol Spectrum Disorder (FASD) is one of the most common neurodevelopmental disorders in North America. It is a complex disability, associated with challenges in cognitive, behavioural, and social-emotional functioning, as well as an increased risk of physical and mental health comorbidities, and difficulties in daily living across the lifespan. Previous attempts to characterize the profile of this population have been hampered by differences in data collected across studies, regional discrepancies in terminology and definitions, and a lack of tools to integrate comprehensive datasets.

Methods and analysis: The goals of this study are to use the Canadian National FASD Database, a national repository of FASD assessment-related information, to better understand the functional profile, comorbidities, intervention needs, and difficulties in daily living experienced by individuals assessed for FASD across the lifespan. We will also examine what factors may be the most sensitive predictors of receiving an FASD diagnosis. Data will be analyzed from over 3,500 records collected between 2010 and 2021 (ongoing) from 26 FASD diagnostic clinics in seven provinces and territories. Data collection is ongoing, and analysis will be performed on a bi-annual basis to continue to hone our understanding of the profiles, needs, and outcomes of individuals assessed for FASD in Canada. This research is critical for refining FASD assessment and diagnostic practice, enabling accurate and early identification of individuals with FASD, and connecting individuals with FASD and their families to comprehensive and effective services and resources to support healthy developmental trajectories. **Ethics and dissemination:** Ethics approval for the National FASD Database Project was obtained from the Ottawa Health Science Network Research Ethics Board. As new knowledge is gained from this project, findings will be disseminated through publications, presentations, and feedback to participating clinics, with the ultimate goal of informing FASD research, practice, and policy.

Key words: fetal alcohol spectrum disorder; prenatal alcohol exposure; assessment and diagnosis; national database; developmental trajectories

Strengths and limitations of this study

1. The Canadian National FASD Database is the first and only existing standardized patient-level database of individuals assessed for FASD in Canada, which allows for the identification of trends related to the prevalence and diagnosis of FASD and associated features.

2. Ongoing data collection enables the monitoring of changes in population-level profiles, needs, and experiences of individuals assessed for FASD in Canada, as well as access to timely information to guide FASD research, practice, and policy.

3. The Database was developed in consultation with government stakeholders, clinicians, researchers, and individuals with FASD and their families, ensuring that information collected is relevant and meaningful for individuals with FASD and those who support them.

4. Data is collected from many, but not all, clinics in Canada, and there are several provincial and territorial jurisdictions that are not represented in the Database.

5. Information collected is cross-sectional, limiting our ability to explore longitudinal trends or follow the developmental trajectories of individuals with FASD across the lifespan.

INTRODUCTION

Health and human development

Health vulnerability and associated developmental trajectories are rooted in the prenatal stage

and first years of life, both of which are critical periods involving complex interactions between

biological, genetic, and environmental conditions. Many determinants of health contribute to optimal

development and are relevant for all human beings, regardless of culture or background. Maternal and

fetal health, the early caregiving environment and family influences, poverty and malnutrition,

neighbourhood factors, and the broader socio-political context can all have profound impacts on human

development and healthy outcomes.[1] In the long term, poor physical, mental, and socioemotional

development in childhood is linked to unfavourable outcomes such as school failure, delinquency,

unemployment, and poor health in adulthood.[2]

Researchers have worked hard to identify permissive and protective factors that optimize

developmental outcomes, from preconception through to adulthood. The presence of a diagnosable

medical condition early in life can greatly impact an individual's health trajectory throughout the

lifespan.[3] Data strongly suggest that providing early interventions and supports can have protective

effects, mitigate difficulties in daily living, and provide a foundation for healthier trajectories.[4]

However, in order to achieve these benefits, it is essential that individuals who are at risk of negative

outcomes are accurately identified and connected with appropriate and effective supports.

Developmental trajectories and prenatal alcohol exposure

Prenatal alcohol exposure (PAE) is associated with a broad range of neurodevelopmental and

behavioural needs which, without standardized mechanisms for identification, can remain unaddressed.

When needs are not recognized, individuals with PAE can experience substantial challenges, and critical

opportunities for early interventions to improve outcomes for individuals and families may be missed.[5]

Indeed, researchers have shown that early identification and intervention are some of the most

powerful factors to mitigate the lifelong adverse effects of PAE.[4, 6]

Because of the complex and heterogeneous consequences of PAE, a standardized data

collection protocol using common data fields can be a powerful and comprehensive tool for

understanding PAE and its associated impacts. At a national level, such a protocol allows for the large-

scale examination of the neurodevelopmental effects of PAE, as well as the identification of other social

and environmental factors that may influence outcomes for individuals with PAE. Moreover, it can

improve our understanding of the supports, strategies, and interventions that may reduce challenges

and optimize growth and potential for positive outcomes for individuals with PAE and their families.

Fetal Alcohol Spectrum Disorder

When the brain- and body-based impacts of PAE reach a clinical threshold, individuals may be

diagnosed with Fetal Alcohol Spectrum Disorder (FASD). [7] FASD is a lifelong disability associated with

difficulties in motor function, learning, memory, attention, communication, emotional regulation, and

social skills. Individuals with FASD often require ongoing support with daily living and are at high risk for

compromised developmental trajectories, stemming from the neurodevelopmental impacts of PAE,

compounded by complex biopsychosocial and societal factors and societal. Individuals with FASD often

have extensive patterns of impairment with co-occurring physical and mental health conditions that

influence their clinical presentation, treatment recommendations, and potential outcomes. [5, 8-10]

They also often experience early [11] and ongoing environmental adversity [5, 6, 12] and disruption in

the caregiving environment [13, 14] which can impact social, behavioural, and emotional development.

[13, 15, 16] Difficulties with daily living are common among individuals with FASD, including problems

with school and employment; independence and housing; mental health and substance use challenges;

and interaction with the justice system. [5, 6] That said, there is very limited research that focuses on

the strengths of individuals with FASD, and how to achieve successful outcomes, and there is a critical

need to develop and implement strengths-based approaches and interventions for this population. [17]

For example, in one study, researchers identified predictive factors that contribute to success in

occupational performance in youth and adults with FASD, [18]and in another small study reported on

factors that influence success in school, [19] and others have reported on factors that contribute to

positive outcomes among adults with FASD who are involved in the justice system. [20]

FASD affects approximately 4% of the Canadian population and is a complex social and public

health issue. [21, 22] Individuals with FASD are an exceptionally complex and heterogeneous group, and

there is a strong interest among researchers and clinicians in characterizing the profiles, needs, and

experiences of these individuals. [23, 24] However, there are challenges with characterizing individuals

with FASD, such as inconsistent definitions of the disability, varying diagnostic systems and approaches,

as well as the resource-intensive multidisciplinary diagnostic process itself. Attempts to compare data

across FASD studies have largely failed because of the discrepancies in these definitions and approaches.

These challenges highlight the potential utility of a consistent, nation-wide database to inform FASD

research, practice, and policy.

Measuring FASD at the population level in Canada

In Canada, there is a paucity of population-level information about individuals with PAE and

FASD, which is critical for building meaningful, cost-effective, and appropriately distributed

programming and interventions. Over the past decade, Canadian researchers have sought to address

this gap by working together to develop and contribute to a standardized database with a common set

of indicators. The Universal FASDataForm Project was initiated in 2010 in collaboration with Canadian

FASD diagnostic clinics to determine if standardized collection of assessment-related data was a

possibility, and then subsequently to generate the first clinical dataset for FASD, and identify trends and

modalities related to prevention, prevalence, and diagnosis of FASD. [25] The FASDataForm was revised

in 2015 to refine the process of collecting and comparing common data indicators, resulting in the

updated (and renamed) National FASD Database Project. The main purpose of the Database Project is to

capture information related to the assessment and diagnosis of FASD in Canada, including information

on the physical and mental health needs, functional challenges, and difficulties in daily living

experienced by individuals presenting for FASD assessment across the country.

In the current study, our goal is to investigate the profile and experiences of individuals assessed

for FASD in Canada. Analysis of data from the Database will allow us to interpret and disseminate

findings on characteristics, associated features, and experiences of individuals presenting for an FASD

assessment. The study is guided by the following research questions:

1. *What is the neurodevelopmental profile of individuals assessed for FASD in Canada? How does it*

   compare to profiles of individuals assessed for FASD in other countries?

2. *What are the physical and mental health comorbidities associated with FASD? How do these*

   rates compare to the general population?

3. *What are the most sensitive predictive factors for an FASD diagnosis?*

   a. *Which non-diagnostic factors are the most strongly predictive of FASD?*

   b. *Which diagnostic and individual factors are the most strongly predictive of FASD?*

4. *What are the most common recommendations for interventions for individuals assessed for*

   FASD?

5. *What factors may contribute to or protect against the difficulties in daily living associated with*

   FASD?

METHODS AND ANALYSIS

Data source and variables

The National FASD Database is an ongoing data repository comprised of clinical and diagnostic

findings for individuals of all ages presenting for an FASD assessment to participating clinics (n = 26)

from seven provinces and territories in Canada. The Database contains responses from a 287-item

bilingual (English or French) questionnaire, completed online through the RedCap platform, usually by a

clinic intake co-ordinator. Data fields are populated based on chart review of each individual who has

completed the FASD assessment process. The Database includes records generated over two

data collection periods between 2010 and 2021, with ongoing entry.

The Database captures a wide range of information including individual demographics, referral

source and reasons for referral, living situation, family history of FASD, prenatal exposure to alcohol and

other teratogens, and early life adversity. Aligning with the current Canadian Diagnostic Guideline

criteria,[7] data is recorded for each individual on confirmation of PAE above risk levels[i], measurement

of sentinel facial features (SFF)[ii], assessment of neurodevelopmental functioning in 10 domains[iii], and

FASD diagnostic outcome. Associated features of FASD are also recorded, as well as comprehensive

information about the client's physical and mental health and wellbeing, including comorbidities,

medication, substance use, and difficulties in daily living. Finally, data is collected on recommendations

for intervention, and on whether these recommended services are available near the client's home (see

Appendix 1 for full questionnaire, and Table 1 for data collected for this study).

Table 1. Data collected.

Demographics	Age; gender; living situation; region
Historical data	Prenatal exposure to other substances; family history of FASD; trauma; attachment issues; physical or sexual abuse
Diagnostic criteria	Confirmation of PAE; facial measurements; neurodevelopmental functioning
Diagnostic outcome	FASD with SFF; FASD without SFF; At Risk for Neurodevelopmental Disorder (NDD)/FASD; No FASD
Associated features	Sleep problems; sensory sensitivities; sensory processing issues; slow processing speed; gender identity issues

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[i] Under the Canadian Diagnostic Guideline, above-risk PAE threshold is defined as ≥7 standard drinks per week, or ≥2 episodes of drinking of ≥4 drinks on the same occasion. FASD with SFF may be diagnosed in the absence of confirmed above-risk PAE given the specificity of simultaneous presentation of three SFFs to PAE.

[ii] There three features include: 1) palpebral fissure length ≥2 standard deviations below the mean (<3rd percentile), 2) philtrum rated 4 or 5 on a 5-point scale of the University of Washington (UW) Lip-Philtrum Guide, and 3) upper lip rated 4 or 5 on a 5-point scale of the UW Guide.[1]

[iii] The 10 neurodevelopmental domains, as outlined in the Canadian Diagnostic Guideline, include: motor skills; neuroanatomy/neurophysiology; cognition; language; academic achievement; memory; attention; executive function, including impulse control and hyperactivity; affect regulation; and adaptive behaviour, social skills or social communication.

Physical health comorbidities	Congenital malformations; auditory deficit; visual deficit; growth restriction; failure to thrive; microcephaly; neurological conditions; head and neck issues; cleft lip/palate; cardiovascular conditions; respiratory problems; endocrinological condition; musculoskeletal condition; infectious disease
Mental health comorbidities	Intellectual disability; attention deficit hyperactivity disorder; attachment disorder; developmental coordination disorder; language disorder/impairment; Tourette syndrome; anxiety disorder; mood disorder; autism spectrum disorder; bipolar disorder; conduct disorder; oppositional defiant disorder; obsessive compulsive disorder; post-traumatic stress disorder; schizophrenia; substance use disorder; suicidality
Recommendations	Coaching or support; FASD-specific (education or intervention); counselling (support group, individual therapy, or couples/family); respite or daycare; substance use treatment; sexual health education; anger management; spousal abuse intervention; mental health support; basic needs (income support, food bank, safety precautions); guardianship, power of attorney, personal directive, or other substitute decision making; child protection; legal services (legal aid, services for civil or family court issues); allied health services (speech and language pathologist, occupational therapy, behaviour therapy); medication/psychopharmacology or medical referral; accommodations/adaptation in environment, expectations, supports, or routine; anticipatory guidance/prevention; reassessment
Difficulties in daily living	School problems (requiring teacher assistants, expulsion/suspension); employment problems; problems with living independently; housing problems (requiring assisted or sheltered housing); legal problems (victimization, offending, custody/family court issues, incarceration)

As of June 2021 the Database contained more than 3,500 records collected between 2010 and 2021. All individuals were evaluated by a multi-disciplinary team according to the Canadian Diagnostic Guidelines for FASD. [7] Of the individual records that included a diagnostic outcome, 62% received an FASD diagnosis (53% without SFF and 9% with SFF), and 11% were designated At-Risk of NDD/FASD. The mean age of individuals was 14 years old (range 0 to 60 years), and 59% of the sample identified as male.

Patient and public involvement

Anecdotally, patients, clinicians, and families have reported that they want to learn about FASD and its presentation with respect to brain impairment and physical and mental health comorbidities and, most importantly, bring a critical perspective to the work. The goal of this enhanced understanding is to inform more targeted and effective supports and services. Individuals with FASD want to know if their experiences are similar to the experiences of others with the same diagnosis, so they can

contribute to the advancement of research. [26] Recognizing the valuable perspectives of individuals

with FASD and their family members, as well as the clinical expertise of FASD diagnosticians, these

stakeholders played an integral role in the development and design of the National Database. Data fields

in the Database and their indicators were developed by a rigorous process involving the input of

diagnosticians and family members of those with FASD (the public), and adults with FASD (patients)

across Canada and internationally. Feedback was sought from these stakeholders to ensure that data

collection would be feasible and analysis would provide meaningful information and results.

Process of stakeholder engagement

In 2005, the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) administered

a survey to the designated Departmental leads from the seven provincial/territorial ministries that

supported the research to identify current and future priorities for FASD-related research, projects, and

programs. One of the top identified priority areas was to build the capacity of multidisciplinary

diagnostic clinics to work together to contribute evidence to the field of FASD diagnosis in Canada. In

order to better understand the gaps and opportunities in this area, CanFASD hosted a National Forum

and invited representatives from every FASD diagnostic clinic in Canada, caregivers who represented

families with FASD, as well as senior researchers in the field of FASD diagnosis at the time. One hundred

eighteen participants met over a two-day period for facilitated discussions focussed on the following

questions:

- In what ways can cross-regional networking of FASD clinical information enhance or advance

  clinical research and knowledge transfer?

- What are the potential conflicts of interest and solutions that need to be considered?

- How should data be managed and controlled? What issues must be considered in data

  collection, data transfer, data storage, data access, data usage, and data ownership?

- How can diagnostic clinics across Canada work together over the next six months to develop a process for a dataset that would be clinically relevant and helpful in knowledge transfer?

Forum participants identified a critical need for standardized data collection by FASD diagnostic clinics across Canada, based on simioar norms and using the same set of neuropsychological tests across clinics. They concluded that having all Canadian clinics contribute to a common dataset would provide an adequate sample size to develop Canadian norms for measures with existing norms derived from other countries (i.e., growth charts). It was also anticipated that a common dataset would lead to a more accurate and helpful diagnostic system, including physical measures (dysmorphology), brain images, and functional (psychometric) measures of the brain.

A working group was then developed to translate the recommendations of the National Forum into a process for data collection. Working group members were invited by CanFASD, based on experience and expertise in the field of FASD diagnosis. Members included paediatricians (n = 3), a clinical geneticist (n = 1), social workers (n = 2), FASD diagnostic clinic coordinators (n = 4), psychologists (n = 4), parents of individuals with FASD (n = 2), speech and language pathologists (n = 2), and FASD researchers (n = 2). The group had representation from eastern, western, and central Canada and met in person for four days over the course of one year (2006). From these meetings, datafields were developed that were based upon the diagnostic criteria of the 2005 Canadian Guidelines for Diagnosis [27] currently in use at that time. Each datafield was discussed individually and combined into a form, which was streamlined as much as possible to reduce undue burden to data entry personnel. The ultimate goal of the form was to provide data that would:

- Be meaningful to FASD diagnostic clinics to help them better understand their population and to anticipate supports and services
- Be meaningful to individuals with FASD and their families to better understand their disability and to receive effective recommendations

- Contribute evidence to the FASD research field

- Help policy makers with information they need to advocate for and to implement policies, programs, and services related to FASD in their jurisdictions.

The data collection form was then piloted with two of Canada's largest diagnostic clinics who each used it for five patients. Feedback from the pilot was incorporated into the form, and in 2007-2008 the form was sent to every diagnostic clinic in Canada, along with a data dictionary and instructions. Clinics were contacted to guage their interest and invited to an introductory teleconference with the working group. A template for patient consent and for ethics application was also provided. Over the next four years, clinics navigated the process of establishing datasets in their jurisdications with support from the working group and by 2012, 307 forms were submitted by four provinces.

With publication of the updated FASD Diagnostic Guidelines in Canada [7], it became necessary to update the datafields. The working group surveyed all clinics participating in data collection and received feedback about the process and utility of the data collected (n=48 clinics responded). The working group also shared the form and sought feedback from experts in the United States (n=4), Australia (n=1), and New Zealand (n=2) who also had FASD data collection systems. The working group met in person twice over the next year to refine the form as well as to identify an online platform for data entry and hosting. Two in-person workshops (2 hours each) were hosted with participation from families, individuals with FASD, clinicians, researchers, and clinic coordinators who were attending FASD conferences and wished to attend (n=68). The focus of discussion during these workshops was on the datafields and the process for data collection via the new online platform. Feedback was incorporated by the working group, and the online "Dataform" was created in both English and French. An information package was then sent to each diagnostic clinic in Canada (n=65) along with a clinic code for data entry and access to the online system.

A unique and important element of stakeholder engagement in this project h the involvement of families (the public) and individuals with FASD (patients). These stakeholders participated extensively in developing the datafields that comprise the Database, and helped to define the scope of the dataset, especially related to recommendations. For example, adults with FASD reported that they wanted to obtain more information on the trajectory of physical and mental health comorbidities across the lifespan, and their specific requests were included as indicators. Clinics and families who participated in the development of the Database also helped to define the project's research questions and will continue to do so on an ongoing basis. Regular communication with clinics including conference calls, annual face-to-face meetings, quarterly newsletters, and individual clinic updates allows for ongoing collaboration, data quality assessment, and refinement of the data collection process. To ensure that knowledge from the Database is translated meaningfully, feedback and data are provided on a bi-annual basis to each participating clinic for their own use and comparison with provincial and national aggregate datasets. Results are disseminated in a format that clinics can share with their patients and families. Findings from the Database have also been (and will continue to be) presented at various national and international meetings that are attended by individuals with FASD and their family members.

Data analysis plan

Statistical analyses will be performed bi-annually on datasets extracted in the fall (September 30) and spring (April 30) of each year, using SPSS Statistics v.27 software. All data will be grouped categorically. For demographic information, data will be coded as follows: age cohort (0-5 years, 6-12 years, 13-17 years, 18+ years), gender (male, female, other), living situation (independent, with biological mother, biological father, other family member[s], foster care [non-family], adoptive parent[s], group home, homeless, in custody, other), and region (Northern and Western Canada, the Prairies, Central Canada, Atlantic Canada). For diagnostic criteria, confirmation of PAE will be coded as

present, absent, or unconfirmed/unknown; facial measurements will be coded as the number of SFF

present (0, 1, 2, 3, or inconclusive); neurodevelopmental functioning in each domain will be coded

dichotomously (significantly impaired vs. not significantly impaired); and diagnosis will be coded as one

of four outcomes (FASD with SFF, FASD without SFF, At Risk for NDD/FASD, No FASD). All other data will

be coded dichotomously as either absent or present.

Descriptive statistics will be used to characterize the sample for categorical data. We will

conduct Pearson chi-square tests and logistic regression to compare patterns between groups, examine

predictive factors, and explore strengths of association. Where available, prevalence data (e.g.,

comorbidities) will be compared to rates found in neurotypical populations.

Research question 1

What is the neurodevelopmental profile of individuals assessed for FASD in Canada? How does it

compare to profiles of individuals assessed for FASD in other countries?

The neurodevelopmental profile of individuals assessed for FASD will be described in terms of

the frequencies and patterns of neurodevelopmental impairment, and associated difficulties. Profiles

and patterns of each diagnostic criterion (i.e., confirmation of PAE, facial measurements,

neurodevelopmental functioning) will be compared between diagnostic outcomes, age cohorts, and

genders. Findings in this area will provide valuable information about the profile of needs of individuals

with FASD, and improve our understanding of where interventions may be targeted to improve

outcomes for individuals with FASD. In addition, we will examine how the profile of neurodevelopmental

needs in the Canadian population of individuals assessed for FASD compares to that in other countries.

This will be possible through our established partnerships with FASD experts, researchers, and clinicians

in Australia, the United Kingdom, and the United States, all of whom have been working to develop their

own national FASD databases similar to that in Canada.

Research question 2

What are the physical and mental health comorbidities associated with FASD? How do these rates compare to the general population?

The frequencies and patterns of health comorbidities among individuals assessed for FASD will be examined, and compared across diagnostic outcomes, age cohorts, and genders. The strengths of association will be examined between physical and mental health comorbidities and diagnostic outcomes, pattern of brain impairment, and difficulties in daily living. This information will allow for a more holistic and comprehensive understanding of the needs of individuals with FASD across the lifespan and will uncover areas of difficulty that may warrant additional services and supports. To compare the rates of co-occurring physical and mental health conditions in FASD with those in the general population, we will utilize existing data published in the academic (e.g., [28,29]) and grey (e.g., [30]) literature.

Research question 3

A. Which non-diagnostic factors are the most strongly predictive of FASD?

With this question, we aim to identify the combinations of demographic, historical, physical and mental health, and adversity factors that are most strongly associated with being diagnosed with FASD for different age cohorts and genders. We will also explore the strengths of association between predictive factors and FASD diagnosis (any FASD diagnosis and specific FASD diagnostic categories). Predictive models will be developed to determine sensitivity and specificity of combinations of factors associated with being diagnosed with FASD. It is anticipated that findings from these analyses will further refine FASD diagnostic criteria, and lead to more sensitive screening tools across the life span.

B. Which diagnostic and individual factors are the most strongly predictive of FASD?

Diagnostic criteria data will be analysed collectively, independently, and interdependently to explore which criteria may always co-occur, which are exclusive and predictive of FASD, and how non-

diagnostic factors including age, gender, history, or comorbidities may influence whether an individual

receives an FASD diagnosis.

Research question 4

What are the most common recommendations for interventions for individuals assessed for FASD?

The frequency and pattern of recommendations made for each diagnostic outcome, age cohort,

gender, and region will be examined. We will also explore whether and how different types of

recommendations are associated with specific areas of brain impairment and other physical and mental

health comorbidities. Recommendations will be compared across regions to develop intervention maps

for understanding what services are needed, and where they may be lacking. This information will allow

us to better understand practical areas where individuals with PAE require support across their lifespan,

and what factors influence the recommendations made. This information will be useful for clinicians to

influence policy and practice and advocate for consistency in service availability across the country.

Research question 5

What factors may contribute to or protect against the difficulties in daily living associated with FASD?

To explore this question, we will characterize and compare difficulties in daily living across

diagnostic outcomes, age cohorts, and genders. We will also examine the strengths of association

between difficulties in daily living and demographic and historical factors, diagnostic criteria,

comorbidities, and associated features. Although data in the Database is cross-sectional, this

examination will allow us to identify factors that may be related to higher rates of difficulties in daily

living across the life span, and circumstances within which supports may be introduced and optimized.

ETHICS AND DISSEMINATION

Ethics approval for this project was obtained from the Ottawa Health Science Network Research

Ethics Board (protocol # 20160423-0H1), and is renewed on an annual basis. The Database is hosted on

the secure RedCap platform at the University of Alberta, in Edmonton, Alberta, Canada. RedCap is an

important tool for data access, linkages, and mobilization. Upon agreeing to participate in the project, clinics receive a random identification code, and the principal investigator and statistics team is blind to the coding.

Researchers who wish to use the data for their own work are required to obtain approval from their own institutional ethics boards, and apply to a Database oversight committee. Applications must align with the intent and ethics of the overall project. On approval, an anonymised, aggregated dataset is downloaded from the server and sent to the researchers via a secure, password-protected link. This external use of data stimulates the development of new research questions and collaborations, and expands the potential impact of the Database.

Several studies have been published from the Database [5, 25, 31] and many more are underway. As new knowledge is gained, findings will be disseminated through presentations at local, national, or international meetings; publications in academic and grey literature; and regular feedback to participating clinics, all with the goal of informing FASD research, practice, and policy.

DISCUSSION

The National FASD Database provides rich information, both medical and behavioural, about individuals assessed for FASD in Canada across the lifespan. This information contributes evidence related to diagnostic criteria, determining the need for and availability of intervention supports, and stimulating further research. Information collected in the Database will improve our understanding of the challenges, clinical profiles, functional needs, and outcomes of Canadians who are exposed to alcohol prenatally. We know that Canadians presenting at FASD clinics experience substantial difficulties navigating daily life, [5] and continued data collection and analysis through the Database has important implications for guiding practice and policy responses to improve quality of life for these individuals and their families. The Database also captures important information about individuals who are assessed for FASD but are not diagnosed. Although evidence in this area is limited, researchers suggest that clinically-

referred individuals with PAE who do not meet the criteria for a formal diagnosis may nonetheless

experience complex needs requiring timely care. [5,32] Information on the functional needs and

complex presentations of all Canadians with PAE allows for a comprehensive understanding of areas

where supports are needed, and guides efforts to provide the most appropriate services and

interventions.

Collecting information from Canadians with PAE across the lifespan also allows us to understand

more about the trajectory of FASD in Canada, whether the common experiences of Canadians with FASD

change systematically over time, and how services and policies should be modified to meet these

changing needs. The Database allows us to compare the profiles and characteristics of Canadians with

FASD to other subgroups of the population to identify unique or pressing needs. Examining trends in

FASD data at a regional level will allow us to determine whether the needs of individuals with FASD

differ in specific locations, and whether tailored approaches to service delivery are needed and available

in different parts of the country. Similarly, findings from the Database Project will reveal important

information about the gaps between FASD diagnosis and service availability for families impacted by

FASD. Individuals with FASD and their caregivers require access to coordinated supports and services

that are informed by the pattern of brain impairment identified during the diagnostic assessment.[29] In

the current service system, these supports may be lacking, and findings from the Database will highlight

the most common priorities for intervention, as well as the most significant gaps in FASD services.

Finally, the Database provides a structure for active communication and collaboration among all

clinics in Canada that provide FASD diagnostic services. Already, there is preliminary data to suggest that

FASD clinicians are operating with a good deal of consistency across the country, [33,34] which may in

part be attributable to engagement with the National Database. This coordinated approach allows for a

consistent application of FASD best practices, a cohesive community of practice, and a stronger network

of experts working together to support improved outcomes for individuals with FASD and their families.

Limitations and challenges

The Database Project has several limitations. First, despite our goal to have every diagnostic

clinic in Canada (approximately 60 to date) contributing to the Database, some jurisdictions are not

represented. We have made significant efforts to recruit clinics from every Canadian province and

territory, and to reduce barriers to participation, we continue to assist clinics with their local ethics

applications. Nonetheless, there are regional gaps in the data that limit nation-wide conclusions.

Second, because the information in the Database is cross-sectional, it is not possible to examine

longitudinal trends or to follow-up with individuals to see how their profiles and needs change

throughout their lifespan. However, because data is collected from individuals at various life stages,

general snapshot observations can be made about different experiences or challenges that may be most

relevant for individuals with FASD as they age. Relatedly, with this project, we will be able to identify

important focal points that warrant follow-up using longitudinal approaches to best understand this

population. In addition, since the Database is a clinical dataset rather than a true research database,

there is no control group of individuals who are neurotypical, or of individuals who have PAE but do not

experience problems significant enough to trigger a referral for assessment. Therefore, in order to

contextualize findings from the Database, we typically must compare results with existing literature

from neurotypical populations (e.g., prevalence of mental health disorders). Importantly, although the

Database provides a mechanism for uncovering areas of *relative* strength or absence of deficit among

individuals assessed for FASD, in future iterations of the Database we will consider more targeted

approaches and methods for identifying strengths-based characteristics, skills, and assets that may be

leveraged to support positive outcomes in this population.

Additional limitations relate to the data collected on PAE. Currently, the Database does not

include information about amount or type of alcohol consumed, nor does it include the specific timing

of exposure during pregnancy. Moreover, although "confirmed absent" PAE refers to no alcohol

exposure, and confirmed PAE indicates exposure "at or above risk levels" as specified in the Canadian

Diagnostic Guideline [7], exposure levels between 'none' and 'above risk' are not captured. Most (if not

all) clinics only accept individuals for an assessment if they meet or exceed the minimum PAE threshold.

The legal, ethical, and administrative processing that is necessary to conduct research of this

scope across jurisdictional lines is possible, but arduous, and may limit the level of detail included in the

Database. A great deal of consideration was given to the development of each question, balancing the

need to derive meaningful information with the priority that data entry must not be burdensome for

clinics. However, through clinic consultation, we have learned that additional valuable information

would be available for collection in future iterations of the Database. For instance, although in-depth

information regarding the amount and timing of PAE was thought to be unattainable at the time of the

Database development, we have learned that most clinics have access to this information and that it

would be feasible to collect in the future.

Finally, although the Database is structured according to the Canadian FASD Diagnostic

Guidelines, [7] and guidance is provided to clinics for measuring and reporting on the diagnostic criteria,

including a Data Dictionary, information in the Dataset still comes through various avenues. These

include self-report, record review, or screening tools, and this variability may result in inconsistent

reporting. In order to mitigate this, participating clinics have been provided with a list of recommended

assessment tools for each of the measurements (as per the current Canadian diagnostic guideline),

where appropriate. Clinics also use a collaborative online platform to share ideas and experiences

related to data field interpretation and data entry, in order to increase consistency in the use of the

Database. Without funding for each clinic, it is necessary to rely on the enthusiasm and investment of

clinicians to sustain the partnership. Without the efforts of the participating clinics and the individuals

and families who consent to their data collection, the Database would not be possible.

CONCLUSION

Canada's National FASD Database provides an important framework for characterizing and

exploring the needs and outcomes of individuals with PAE across the life span. The comprehensive and

nation-wide scope of the Database enables researchers to examine questions that have not previously

been possible to explore. The Database provides a unique and timely opportunity to monitor the

prevalence of FASD and associated health comorbidities at a population level, as well as evidence to

determine optimal interventions mapped to physical, mental, and neurodevelopmental issues and

optimize developmental trajectories of individuals prenatally exposed to alcohol. The clinical

presentation of Canadians with PAE and FASD is highly complex, and information derived from the

Database provides direct evidence of areas where supports are needed. Critically, this information can

guide our efforts to provide the most appropriate services and interventions to support positive

outcomes for individuals with FASD, their caregivers, families, and communities.

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AUTHORS' CONTRIBUTIONS

J Cook lead the conceptualization of the design of this project, the applications for funding and the overall development of the database. K Unsworth lead the recruitment of participants and clinics, development of the knowledge translation plan and the reporting of the work. K Flannigan refined research questions, piloted the survey tool and provided interpretation of the data. All authors drafted sections of the manuscript and revised it critically. All approve this final version for publication and agree to be accountable for all aspects of the work.

COMPETING INTERESTS STATEMENT

None to declare.

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CanFASD Dataform

1
2
3
4
5 Preferred language/Langue de préférence: ◯ English ◯ Français
6
7
8
9 DEMOGRAPHIC INFORMATION AND PATIENT CHARACTERISTICS
10
11
12 Identification
13
14 Site ID
15
16   _____
17
18 Country   ◯ Canada
19   ◯ Australia
20   ◯ New Zealand
21   ◯ United States
22   ◯ United Kingdom
23   ◯ France
24   ◯ Other
25
26 Please specify
27   _____
28
29 Province/Territory   ◯ AB
30   ◯ BC
31   ◯ MB
32   ◯ NB
33   ◯ NS
34   ◯ NL
35   ◯ NWT
36   ◯ NU
37   ◯ ON
38   ◯ QC
39   ◯ SK
40   ◯ YK
41
42 Type of assessment   ◯ Initial Assessment
43   ◯ Re-assessment
44   ◯ Follow-up
45
46 If being re-assessed, was the individual previously   ◯ Yes
47 given an "At Risk" designation?   ◯ No
48   ◯ Unknown
49
50
51 Date of Referral
52
53
54
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60

1	Month	◯ January
2		◯ February
3		◯ March
4		◯ April
5		◯ May
6		◯ June
7		◯ July
8		◯ August
9		◯ September
10		◯ October
11		◯ November
12		◯ December

Year

_____

Source of Referral

◯ Social Services Agency (e.g., Child and Family Services agency, community support agency)
◯ Medical Referral
◯ Education System (e.g., school, daycare)
◯ Legal System
◯ Self
◯ Family referral (e.g., biological, foster, adoptive parent)
◯ Other

Specify

_____

Reason(s) for referral

Please check all that apply

☐ Behavioural issues
☐ Learning difficulties
☐ Difficulties with the law
☐ Developmental delays/delays to meet developmental milestones
☐ Adaptive living problems
☐ Confirmed prenatal alcohol exposure
☐ Social skills difficulties
☐ Self-regulation difficulties (feeding, sleeping, sensory)
☐ Reassessment
☐ Follow-up
☐ Establish eligibility for supports (e.g., financial or developmental support programs)
☐ Other

Please specify

_____

Was a screening tool used for referral?   ◯ No   ◯ Yes

Which tool?

_____

Who did the screen?

_____

Date of Diagnostic Assessment

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

Year

_____

Sex   ○ Male   ○ Female

Gender identity   ○ Male   ○ Female   ○ Other

Please specify

_____

Date of Birth

Month	○ January
	○ February
	○ March
	○ April
	○ May
	○ June
	○ July
	○ August
	○ September
	○ October
	○ November
	○ December

Year

_____

Which ethnic group(s) does this person most identify with?

☐ Caucasian
☐ Indigenous
☐ African American
☐ Latin American
☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc.)
☐ West Asian (e.g. Iranian, Afghan, etc.)
☐ Chinese
☐ Filipino
☐ Korean
☐ Japanese
☐ Southeast Asian (e.g. Vietnamese, Cambodia, Laotian, Thai, etc.)
☐ Arab
☐ Other
☐ Unknown

Specify

_____

Current living situation

○ Independent
○ With biological mother
○ With biological father
○ With other family member(s)
○ Foster care (non-family member)
○ Adoptive parent(s)
○ Group home
○ Homeless
○ In custody
○ Other

Specify other family member(s)

_____

Specify

_____

Has a biological parent been diagnosed with FASD?   ○ No   ○ Yes   ○ Unknown

Has a sibling been diagnosed with FASD?

○ No
○ Yes
○ Unknown
○ Not applicable (no siblings)

ASSESSMENT OF PRENATAL ALCOHOL EXPOSURE

Prenatal alcohol exposure is:

○ Absent (Confirmed)
○ Present (Confirmed)
○ Unconfirmed
○ Unknown

Please specify source, if known

_____

Other prenatal exposures:

REDCap

	Absent (Confirmed)	Present (Confirmed)	Unknown
Nicotine	○	○	○
Opiates	○	○	○
Marijuana/cannabis	○	○	○
Cocaine/crack	○	○	○
Methamphetamine/speed	○	○	○
Prescription medications	○	○	○
Other Exposures	○	○	○

Please specify

_____

Other factors

Please check all that apply

☐ Post-natal trauma
☐ Attachment issues
☐ Sexual or physical abuse
☐ Other

Please specify

_____

SENTINEL FACIAL FEATURES

Palpebral fissure norms used:

☐ Canadian norms
☐ Thomas
☐ Scandinavian
☐ Other

Please specify

_____

Palpebral fissure length

○ >-1 SD
○ > -2 SD & < -1 SD
○ < -2 SD

Philtrum smoothness

Score on lip-philtrum guide

○ 1
○ 2
○ 3
○ 4
○ 5

Upper lip thinness

Score on lip-philtrum guide

○ 1
○ 2
○ 3
○ 4
○ 5

Total number of sentinel facial features present

○ 0
○ 1
○ 2
○ 3
○ Inconclusive

NEUROBEHAVIOURAL ASSESSMENT

23-04-2018 13:41

www.projectredcap.org

REDCap

Brain Domain Assessment Results

Please indicate how the following brain domain was assessed

	Not impaired	Significant Impairment	Not Assessed	Incomplete
Motor skills	○	○	○	○
Neuroanatomy/Neurophysiology	○	○	○	○
Cognition	○	○	○	○
Language	○	○	○	○
Academic achievement	○	○	○	○
Memory	○	○	○	○
Attention	○	○	○	○
Executive function including impulse control	○	○	○	○
Affect Regulation	○	○	○	○
Adaptive behaviour, social skills, or social communication	○	○	○	○

Full scale IQ
○ Less than 70
○ 70
○ 71-85
○ greater than 85
○ Unable to calculate

Diagnosis
○ FASD with sentinel facial features
○ FASD without sentinel facial features
○ At risk for neurodevelopmental disorder and FASD associated with prenatal alcohol exposure
○ No FASD Diagnosis

Do you use another diagnostic schema to record information (i.e. 4-digit code)?   ○ No   ○ Yes

Please provide the 4-digit diagnostic code

_____

Other associated features

Please check all that apply
☐ Sleep problems
☐ Sensory sensitives
☐ Sensory processing
☐ Trauma
☐ Slower processing speed
☐ Gender identity
☐ Other

Please specify

_____

Other diagnoses

Note: Assessment did not have to occur at this clinic.

	No (Assessed but not diagnosed)	Yes (Assessed and diagnosed)	Not assessed
Congenital malformations	◯	◯	◯
Intellectual disability	◯	◯	◯
ADD/ADHD	◯	◯	◯
Attachment disorder	◯	◯	◯
Developmental coordination disorder	◯	◯	◯
Language disorder/impairment	◯	◯	◯
Auditory deficit	◯	◯	◯
Visual deficit	◯	◯	◯
Tourette's	◯	◯	◯
Anxiety disorder	◯	◯	◯
Autism Spectrum Disorders	◯	◯	◯
Bipolar disorder	◯	◯	◯
Conduct disorder	◯	◯	◯
Mood disorder	◯	◯	◯
Obsessive compulsive disorder	◯	◯	◯
Personality disorder	◯	◯	◯
PTSD	◯	◯	◯
Schizophrenia	◯	◯	◯
Substance abuse disorder	◯	◯	◯
Suicide attempt(s)/Ideation	◯	◯	◯
Oppositional defiant disorder	◯	◯	◯
Other	◯	◯	◯

Please specify

_____

MEDICAL HEALTH HISTORY

Growth restriction   ◯ No   ◯ Yes

Please specify height and weight percentiles

_____

Microcephaly   ◯ Yes   ◯ No

Failure to thrive   ◯ yes   ◯ No

Neurological conditions   ◯ No   ◯ Yes

Please specify

_____

Mental health   ◯ No   ◯ Yes

REDCap

Please specify

_____

Head and neck issues   ◯ No   ◯ Yes

Please specify

_____

Cleft Lip Palate   ◯ Yes   ◯ No

Cardiovascular conditions   ◯ No   ◯ Yes

Please specify

_____

Respiratory system   ◯ No   ◯ Yes

Please specify

_____

Endocrinological conditions   ◯ No   ◯ Yes

Please specify

_____

Musculoskeletal   ◯ No   ◯ Yes

Please specify

_____

Infectious diseases   ◯ No   ◯ Yes

Please specify

_____

Other   ◯ No   ◯ Yes

Please specify

_____

MEDICATION

	No	Yes
Omega-3	○	○
Choline	○	○
Glutamine	○	○
Aripiprazole	○	○
Vortioxetine	○	○
Minocycline	○	○
Bupropion	○	○
Buspirone	○	○
Clozapine	○	○
Melatonin	○	○

Please list all other current medications

Stimulants

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-depressants

Medication 1: _____

Medication 2:

_____

Medication 3:

_____

Medication 4:

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Medication 5:

_____

Medication 6:

_____

Medication 7:

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Medication 8:

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Medication 9:

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Medication 10:

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Anti-psychotics

Medication 1:

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Medication 2:

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Medication 3:

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Medication 4:

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Medication 5:

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Medication 6:

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Medication 7:

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Medication 8:

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Medication 9:

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Medication 10:

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Birth Control Pills

Medication 1:

_____

Medication 2:

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Medication 3:

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Medication 4:

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Medication 5:

_____

Medication 6:

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Medication 7:

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Medication 8:

_____

Medication 9:

_____

Medication 10:

_____

Hormone replacement therapy

Medication 1:

_____

Medication 2:

_____

Medication 3:

_____

Medication 4:

_____

Medication 5:

_____

Medication 6:

_____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-hypertensives

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4: _____

Medication 5: _____

Medication 6: _____

Medication 7: _____

Medication 8: _____

Medication 9: _____

Medication 10: _____

Anti-convulsants

Medication 1: _____

Medication 2: _____

Medication 3: _____

Medication 4:	_____
Medication 5:	_____
Medication 6:	_____
Medication 7:	_____
Medication 8:	_____
Medication 9:	_____
Medication 10:	_____

Other

Medication 1:	_____
Medication 2:	_____
Medication 3:	_____
Medication 4:	_____
Medication 5:	_____
Medication 6:	_____
Medication 7:	_____
Medication 8:	_____
Medication 9:	_____
Medication 10:	_____

Are any of the following substances currently being used/misused?

	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Opiates	○	○	○
Solvents	○	○	○
Crack/Cocaine	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following substance use/misuse treatments currently being accessed?

	No	Yes	Unknown
Alcohol	○	○	○
Tobacco	○	○	○
Marijuana/cannabis	○	○	○
Other	○	○	○

Please specify

_____

Are any of the following currently being experienced?

	No	Yes	Unknown	To be followed up after clinic
Teachers assistants prior to diagnosis	○	○	○	○
School expulsion/suspension	○	○	○	○
Employment problems	○	○	○	○
Needs help living on own	○	○	○	○
Needs assisted or sheltered housing	○	○	○	○
Legal problems: Victim	○	○	○	○
Legal problems: Offender	○	○	○	○
Custody issues/family court	○	○	○	○
Special courts jail	○	○	○	○
Regular courts jail	○	○	○	○
Incarcerated	○	○	○	○

Which of the following recommendations were made?

		No	Yes	Yes, but service not available
1	Coaching	○	○	○
2	Support (individual or group)	○	○	○
4	FASD Education	○	○	○
5	FASD Early intervention	○	○	○
7	Counselling support group	○	○	○
8	Counselling or individual therapy	○	○	○
9	Couple/family counselling	○	○	○
11	Substance abuse counselling/therapy	○	○	○
13	Respite	○	○	○
15	Sexual Health Education	○	○	○
16	Anger Management	○	○	○

		No	Yes	Yes, but service not available
19	Child protection	○	○	○
20	Spousal abuse intervention	○	○	○
22	Mental health support	○	○	○
23	Income support	○	○	○
24	Food bank	○	○	○
26	Emergency housing/shelter	○	○	○
27	Daycare	○	○	○
29	Guardianship	○	○	○
30	Power of Attorney	○	○	○
32	Personal directive	○	○	○

	No	Yes	Yes, but service not available
Legal aid	○	○	○
Services for civil court issues	○	○	○
Services for family court issues	○	○	○
Speech and language pathologist	○	○	○
Behaviour Therapy services (CBT, ABA, IBI, and other BT supports)	○	○	○
Medication/psychopharmacology	○	○	○
Occupational therapy	○	○	○
Accommodations/adaptation in environment, expectations, supports used, or routine	○	○	○
Anticipatory Guidance/Prevention: for the purpose of increasing awareness and/or decreasing risk of potential future problems	○	○	○
Safety: Precautions to be taken or specific measures to deal with safety concerns	○	○	○
Reassessment	○	○	○
Other substitute decision-making options	○	○	○
Other legal services	○	○	○
Medical referral	○	○	○
FASD-specific intervention	○	○	○

RENSEIGNEMENTS DÉMOGRAPHIQUES ET CARACTÉRISTIQUES DES PATIENTS

Identification

Code de site

_____

Pays
- ○ Canada
- ○ Australie
- ○ Nouvelle-Zélande
- ○ États-Unis
- ○ Royaume-Uni
- ○ France
- ○ Autre

Veuillez préciser

_____

1	Province/Territoire	○ AB
2		○ CB
3		○ MB
4		○ NB
5		○ NE
6		○ TN
7		○ TNO
8		○ NU
9		○ ON
10		○ QC
11		○ SK
12		○ YK

14 Année du diagnostic

_____

17 Type de diagnostic:

○ Une évaluation initiale
○ Une réévaluation
○ Un suivi

22 Date de la référence

25 Mois

○ janvier
○ février
○ mars
○ avril
○ mai
○ juin
○ juillet
○ août
○ septembre
○ octobre
○ novembre
○ décembre

38 Année

_____

41 Source de la référence

○ Agence des services sociaux (par ex. agence de services à l'enfance et à la famille, agence de soutien communautaire)
○ Recommandation médicale
○ Système éducatif (par ex. école, garderie)
○ Système judiciaire
○ Auto-recommandation
○ Recommandation de la famille (par ex. parents biologiques, adoptifs, famille d'accueil)
○ Autre

52 Veuillez préciser

_____

Raison de la référence

Veuillez cocher tout ce qui s'applique

☐ Problèmes de comportement
☐ Difficultés d'apprentissage
☐ Problèmes avec le système judiciaire
☐ Retards de développement/délais en matière de stades de développement
☐ Problèmes de vie adaptatifs
☐ Exposition prénatale à l'alcool confirmée
☐ Difficultés en matière d'aptitudes sociales
☐ Difficultés d'autorégulation (par ex. nourriture, sommeil, sens)
☐ Réévaluation
☐ Suivi
☐ Pour établir l'éligibilité pour un soutien (financier ou programmes de soutien au développement)
☐ Autre

Veuillez préciser

_____

Est-ce qu'un outil de dépistage a été utilisé
pour la référence?   ◯ Non   ◯ Oui

Quel outil?

_____

Qui a effectué le dépistage?

_____

Date de l'évaluation multidisciplinaire

Mois   ◯ janvier
                                                           ◯ février
                                                           ◯ mars
                                                           ◯ avril
                                                           ◯ mai
                                                           ◯ juin
                                                           ◯ juillet
                                                           ◯ août
                                                           ◯ septembre
                                                           ◯ octobre
                                                           ◯ novembre
                                                           ◯ décembre

Année

_____

Sexe (biologique)   ◯ Homme   ◯ Femme

Genre   ◯ Homme   ◯ Femme
                                                           ◯ Autre

Veuillez préciser

_____

Date de naissance

Mois	◯ janvier
	◯ février
	◯ mars
	◯ avril
	◯ mai
	◯ juin
	◯ juillet
	◯ août
	◯ septembre
	◯ octobre
	◯ novembre
	◯ décembre

Année

_____

Avec quel group ethnique cette personne s'identifie le plus?

☐ Caucasien
☐ Indigène
☐ Afro-Américain
☐ Latino-Américain
☐ Sud-Asiatique (p. ex. Indien de l'Inde, Pakistanais, Sri-Lankais, etc.)
☐ Asiatique occidental (p. ex. Iranien, Afghan, etc.)
☐ Chinois
☐ Philippin
☐ Coréen
☐ Japonais
☐ Asiatique du Sud-Est (p. ex. Vietnamien, Cambodgien, Laotien, Thaïlandais, etc.)
☐ Arabe
☐ Autre
☐ Inconnue

Veuillez préciser

_____

Situation domiciliaire	◯ Indépendant
	◯ Avec mère biologique
	◯ Avec père biologique
	◯ Avec autre famille
	◯ Famille d'accueil (personnes qui ne font pas partie de la famille)
	◯ Parent(s) adoptif(s)
	◯ Foyer
	◯ Sans abri
	◯ En détention
	◯ Autre

Veuillez préciser autre famille

_____

Veuillez préciser

_____

Est-ce qu'un parent biologique a reçu un diagnostic de TSAF?	◯ Non ◯ Oui ◯ Inconnue

Est-ce qu'un frère ou une soeur a reçu un
diagnostic de TSAF

○ Non
○ Oui
○ Inconnue
○ Sans objet (enfant unique)

EVALUATION DE L'EXPOSITION PRÉNATALE À L'ALCOOL

L'exposition prénatale à l'alcool est:

○ Absente (Confirmée)
○ Présente (Confirmée)
○ Non-confirmée
○ Inconnue

Veuillez préciser la source, si connue

_____

Autres expositions prénatales

	Absente (Confirmée)	Présent (Confirmée)	Inconnue
Nicotine	○	○	○
Opiacés	○	○	○
Marijuana	○	○	○
Cocaïne/crack	○	○	○
Méthamphétamine/speed	○	○	○
Médicaments prescrits	○	○	○
Autre expositions	○	○	○

Veuillez préciser

_____

Autres facteurs

Veuillez cocher tout ce qui s'applique

☐ Traumatisme post-natal
☐ Problèmes d'attachement
☐ Abus physique ou sexuel
☐ Autre

Veuillez préciser

_____

TRAITS FACIAUX CARACTÉRISTIQUES

Normes de fentes palpébrales utilisées:

☐ Normes canadiennes
☐ Thomas
☐ Scandinaves
☐ Autre

Veuillez préciser

_____

Longueur de la fente palpébrale

○ >-1 ET
○ > -2 ET & < -1 ET
○ < -2 ET

Caractère lisse du philtrum	○ 1
Score sur le guide lip-philtrum	○ 2
	○ 3
	○ 4
	○ 5

Épaisseur de la lèvre supérieure	○ 1
score sur le guide Lip-philtrum	○ 2
	○ 3
	○ 4
	○ 5

Nombre total de traits faciaux caractéristiques présents	○ 0
	○ 1
	○ 2
	○ 3
	○ Non concluant

ÉVALUATION NEUROCOMPORTEMENTALE

Résultats de l'évaluation des domaines du cerveau

Veuillez indiquer si chaque domaine du cerveau a été évalvé

	Non Altéré	Altéré	Non évalué
Habiletés motrices	○	○	○
Neuroanatomie/Neurophysiologie	○	○	○
Cognition	○	○	○
Langage	○	○	○
Rendement scolaire	○	○	○
Mémoire	○	○	○
Attention	○	○	○
Fonction exécutive (y compris le contrôle des impulsions)	○	○	○
Régulation de l'affect	○	○	○
Comportement adaptatif, aptitudes sociales, ou communication sociale	○	○	○

QI global	○ Inférieur à 70
	○ 70
	○ 71-85
	○ Supérieur à 85
	○ Inconnu/non-calculé

Diagnostic	○ TSAF avec traits faciaux caractéristiques
	○ TSAF sans traits faciaux caractéristiques
	○ À risque de trouble neurodéveloppemental et de TSAF associés à l'exposition prénatale à l'alcool
	○ Pas de diagnostic de TSAF

Utilisez-vous un autre modèle de diagnostic pour enregistrer les informations (c.-à-d. le code diagnostique à 4 chiffres)?	◯ Non ◯ Oui	

Veuillez donner le code diagnostique à 4 chiffres

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Autres caractéristiques associées

Veuillez cocher tout ce qui s'applique

☐ Troubles du sommeil
☐ Sensibilités sensorielles
☐ Déficits de traitement sensoriel
☐ Traumatisme
☐ Vitesse de traitement réduite
☐ identité sexuelle
☐ Autre

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Autre diagnostic

Remarque : L'évaluation n'avait pas à se produire à cette clinique spécifique.

	Non (Évalué)	Oui (Évalué et diagnostiqué)	Non évalué
Malformations congénitales	◯	◯	◯
Déficience intellectuelle	◯	◯	◯
TDA/TDAH	◯	◯	◯
Troubles d'attachement	◯	◯	◯
Dyspraxie	◯	◯	◯
Trouble/Déficience du langage	◯	◯	◯
Déficience auditive	◯	◯	◯
Déficience visuelle	◯	◯	◯
Maladie de Gilles de la Tourette	◯	◯	◯
Trouble anxieux	◯	◯	◯
Troubles du spectre autistique	◯	◯	◯
Trouble bipolaire	◯	◯	◯
Trouble de comportement	◯	◯	◯
Trouble de l'humeur	◯	◯	◯
Trouble obsessif compulsif	◯	◯	◯
Trouble de la personnalité	◯	◯	◯
TSPT	◯	◯	◯
Schizophrénie	◯	◯	◯
Trouble lié à l'abus d'alcool ou d'autres drogues	◯	◯	◯
Tentatives de suicide /idées suicidaires	◯	◯	◯

1   Autres   ○   ○   ○

4   Veuillez préciser

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8   ANTÉCÉDENTS MÉDICAUX

10   Retard de croissance   ○ Non   ○ Oui

13   Veuillez préciser

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16   Troubles neurologiques   ○ Non   ○ Oui

18   Veuillez préciser

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21   Problèmes de santé mentale   ○ Non   ○ Oui

24   Veuillez préciser

_____

27   Problèmes de tête et de cou   ○ Non   ○ Oui

29   Veuillez préciser

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33   Troubles cardiovasculaires   ○ Non   ○ Oui

35   Veuillez préciser

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38   Troubles du système respiratoire   ○ Non   ○ Oui

41   Veuillez préciser

_____

44   Troubles endocrinologiques   ○ Non   ○ Oui

46   Veuillez préciser

_____

50   Problèmes musculosquelettiques   ○ Non   ○ Oui

52   Veuillez préciser

_____

55   Maladies contagieuses   ○ Non   ○ Oui

58   Veuillez préciser

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	Non	Oui
Autres	○	○

Veuillez préciser

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MÉDICAMENTS

	Non	Oui
Omega-3	○	○
Choline	○	○
Glutamine	○	○
Aripiprazole	○	○
Vortioxetine	○	○
Minocycline	○	○
Bupropion	○	○
Buspirone	○	○
Clozapine	○	○
Melatonin	○	○

Veuillez dresser une liste des autres médicaments consommés actuellement

Stimulants

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Antidépresseurs

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Antipsychotiques

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Pilule contraceptive

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Traitement hormonal substitutif

Médicament 1:

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Médicament 2:

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Médicament 3:

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    Médicament 5:

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    Médicament 9:

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    Médicament 10:

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Antihypertenseurs

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    Médicament 1:

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    Médicament 2:

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    Médicament 3:

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    Médicament 10:

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Anticonvulsivants

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Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Autres

Médicament 1:

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Médicament 2:

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Médicament 3:

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Médicament 4:

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Médicament 5:

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Médicament 6:

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Médicament 7:

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Médicament 8:

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Médicament 9:

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Médicament 10:

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Est-ce que les substances suivantes sont présentement consommées/surconsommées?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Opiacés	○	○	○
Solvants	○	○	○
Crack/ cocaïne	○	○	○
Autres	○	○	○

Veuillez préciser

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Est-ce que l'individu en cours d'évaluation poursuivit présentement un traitement concernant une substance consommée/surconsommée ?

	Non	Oui	Inconnu
Alcool	○	○	○
Tabac	○	○	○
Marijuana	○	○	○
Autres	○	○	○

Veuillez préciser

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Est-ce que l'individu en cours d'évaluation se trouve dans une ou plusieurs des situations suivantes?

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	Non	Oui	Inconnu	Suivi à effectuer après clinique
Aides enseignants avant le diagnostic	○	○	○	○
Expulsion/Suspension de l'école	○	○	○	○
Problèmes d'emploi	○	○	○	○
A besoin d'aide pour vivre seul	○	○	○	○
A besoin de logement protégé ou assisté	○	○	○	○
Problèmes juridiques : victime	○	○	○	○
Problèmes juridiques : accusé	○	○	○	○
Problèmes de garde/tribunal de la famille	○	○	○	○
Prison des tribunaux spéciaux	○	○	○	○
Prison des tribunaux réguliers	○	○	○	○
Incarcération	○	○	○	○

Lesquelles des recommandations suivantes ont été faites?

	Non	Oui	Service non-disponible
Encadrement	○	○	○
Soutien (individuel ou de groupe)	○	○	○
Stratégies de communication	○	○	○
Évaluation/Intervention précoce en matière de TSAF	○	○	○
Groupes de soutien/services de conseil	○	○	○
Services de conseils ou thérapie individuelle	○	○	○
Thérapie de couple/familiale	○	○	○
Services de conseils/thérapie en matière d'abus d'alcool ou de toxicomanie	○	○	○
Répit	○	○	○
Intervention contre la violence à l'égard des aînés	○	○	○

		Non	Oui	Service non-disponible
1	Protection de l'enfance	○	○	○
2 3 4	Intervention contre la violence conjugale	○	○	○
5 6 7	Soutien en matière de santé mentale	○	○	○
8	Aide au revenu	○	○	○
9	Banque alimentaire	○	○	○
10 11	Logement/Abri d'urgence	○	○	○
12	Garderie	○	○	○
13 14	Tutelle	○	○	○
15	Procuration	○	○	○
16 17	Instructions personnelles	○	○	○

		Non	Oui	Service non-disponible
18 19	Aide juridique	○	○	○
20 21 22	Services pour les problèmes au tribunal civil	○	○	○
23 24	Services pour les problèmes au tribunal de la famille	○	○	○
25 26	Orthophoniste	○	○	○
27 28 29	services de thérapie du comportement (ABA/IBI et autres soutiens)	○	○	○
30 31 32	Médicaments/Psychopharmacologie	○	○	○
33 34	Ergothérapie	○	○	○
35 36 37	Logement/Adaptation en environnement, attentes, soutiens ou routine	○	○	○
38 39 40 41 42 43 44	Conseils de prévention et d'orientation: dans le but d'augmenter la sensibilisation et/ ou réduire les problèmes potentiels à venir	○	○	○
45 46 47 48 49	Sécurité : précautions à prendre ou mesures spécifiques pour gérer des inquiétudes en matière de sécurité	○	○	○
50 51	Réévaluation	○	○	○
52 53	Options de prise de décisions alternatives	○	○	○
54 55	Autres services juridiques	○	○	○
56	Autres références médicales	○	○	○

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